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Couples' Experiences after Cancer Treatment:
A Systematic Review and Qualitative Study

Naomi White

Doctorate in Clinical Psychology (DClinPsychol)
The University of Edinburgh
August 2013

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Thesis Abstract

Background: The incidence of cancer is increasing alongside a fall in mortality rates. This has resulted in a growing number of cancer survivors overall, including for colorectal (bowel) cancer. For healthcare services to effectively support recovery and adjustment for survivors and their caregivers, there is a need to develop an understanding of couples' experiences after treatment.

Objectives: The systematic review aimed to identify qualitative research on partners' experiences of cancer caregiving after treatment, and to synthesise findings on partners' psychological adjustment. The primary qualitative study aimed to explore couples' experiences of colorectal cancer services from the perspectives of patients and their partners, focusing on the transition period after treatment.

Methods: For the systematic review, 10 qualitative studies were purposefully sampled to focus on partners' psychological adjustment post-treatment. Findings from these studies were analysed and synthesised using the Framework approach. For the empirical study, semi-structured interviews were conducted separately with a purposeful sample of 10 participants, comprising five patient-partner dyads. Data were analysed using the Framework approach, incorporating dyadic analysis to compare narratives within and between couples.

Results: The synthesis highlighted the importance of considering the patient-caregiver relationship across the cancer trajectory and within the wider context. Specific barriers and facilitators of partners' adjustment related to communication and cohesion, transitions and gradual changes, as well as healthcare and cultural belief systems. The empirical study identified three overarching themes: the process of recovery, the impact of relationship dynamics, and mixed experiences of healthcare services. An additional discussion chapter provided further comparison of the primary research study with the extant literature.

Conclusions: Recovery and adjustment after cancer can be facilitated by a proactive and systemic approach to healthcare. The findings illustrate the significant impact that patients and partners can have on each other and underscore the need for consistency in good clinical practice throughout the recovery process.

Systematic Review

Formatting for the Systematic Review adheres to the author guidelines issued by the journal Psycho-Oncology (Appendix 13), except where these conflict with the University of Edinburgh regulatory standards for the thesis format.

Full Title

Partners' adjustment to cancer caregiving: A systematic review and synthesis of qualitative research

Short title

Partners' adjustment to cancer caregiving

Authors

Naomi White, ^{1, 2}

Emily Newman, ¹

¹ School of Health in Social Science, University of Edinburgh, UK; ²NHS Grampian, Aberdeen, UK

²NHS Grampian, Aberdeen, UK

Corresponding author's details

Naomi White, Roxburghe House, Ashgrove Road, Aberdeen AB25 3BX.

Email: naomi.white@nhs.net

Telephone: 01224 557 080

Abstract

Objective: To systematically identify published qualitative research on partners' experiences of cancer caregiving after treatment and to synthesise findings on partners' psychological adjustment.

Methods: Electronic and manual searches identified 32 studies which met the inclusion criteria. 10 qualitative studies were purposefully sampled to focus on partners' psychological adjustment post-treatment. Findings from these 10 studies were analysed and synthesised using the Framework approach.

Results: The reviewed studies indicated the importance of considering the patient-caregiver relationship across the cancer trajectory and within the wider context. Specific barriers and facilitators of partners' adjustment related to communication and cohesion, transitions and gradual changes, as well as healthcare and cultural belief systems.

Conclusions: A proactive and systemic approach by healthcare services can facilitate successful adjustment for partners over the longer term. Future research should explore further ways of promoting this in clinical practice, addressing issues related to the cultural context, change over time, and relationship dynamics between couples as well as with the healthcare team.

Keywords: *cancer, oncology, qualitative, review, partners, caregiving*

Introduction

The incidence of cancer is increasing alongside a fall in mortality rates [1], resulting in a growing number of cancer survivors who may require caregiving support after treatment. The long-term impact can affect family caregivers [2] who face a broad range of difficulties and unmet needs [3-4], often without accessing adequate support [5-8]. Recent research suggests caregivers can benefit from support across the illness trajectory, including the adjustment period after treatment [2, 9-13].

In the UK alone, unpaid care is estimated to save health services billions of pounds per year [14], emphasising the value of supporting caregivers to sustain their role and avoid burnout [15-17]. Partners can experience caregiving differently from other family caregivers such as parents or children [18]. They often constitute a key source of support for cancer patients, and their well-being has an impact on the patient's own health [19-20]. Therefore, there is evident value in understanding partners' experiences and ways of promoting their well-being. Qualitative methodology can provide detailed exploration of experience, helping to identify needs and priorities as perceived by individuals [21-22]. Qualitative studies on partners' experiences of cancer caregiving have accumulated over recent years, providing a rich body of data on various aspects of partners' lived experiences. These studies explore the impact of different types of cancer and forms of treatment, covering a diverse range of issues [23-29].

A better understanding is needed of the experiences over the longer term for partners of cancer survivors [30]. Emerging evidence suggests that difficulties can persist over years [31] and the nature of caregivers' specific needs may change over time [9,13]. As expressed by one author, "future research priorities should include studies of families dealing with long-term adult survivors. Together, our goal should be to help families thrive, not merely to survive cancer" [32].

In their review of quantitative and qualitative research, Fletcher and colleagues [33] developed a model of cancer family caregiving experience. It outlines stress processes affecting caregivers over the course of the illness. They acknowledged that their review had to sacrifice depth for breadth. It was noted that the patient-caregiver relationship (described

as 'dyadic phenomena') and cancer trajectory were not yet well-conceptualised. They also highlighted contextual factors in need of further development, including socioeconomic and cultural factors, the healthcare system and caregiver's physical health. Therefore, the present review sought to explore these constructs in greater depth. By systematically reviewing qualitative research, findings from a range of studies can be compared without losing the essential context and richness of the original research [34]. The review aimed to systematically identify and synthesise published qualitative research on partners' experiences of cancer caregiving following treatment. Specifically, the focus of the review was on barriers and facilitators of psychological adjustment for partners.

Methods

Search Strategy

The search strategy was an iterative process in which preliminary search results and associated keywords were used to refine the terms, to balance adequate specificity and scope [35]. The difficulty of systematic searching for qualitative literature due to poor indexing and coverage in electronic databases has been acknowledged [36]. Electronic and manual search techniques were used to reduce the risk of missing relevant studies. The electronic search identified 21 publications meeting the inclusion criteria. A further 11 eligible studies were located through manual searching of the reference and citation lists for included studies, hand-searching of key journals, and by contacting principal authors of identified published papers in the topic area. Techniques used to identify articles for inclusion are summarised (Table 1.1) using the 'STARLITE' framework [37].

Selection of Studies

Inclusion and exclusion criteria

The inclusion criteria were English language studies published in peer reviewed journals, which had a qualitative or mixed methods design, and which reported primary data about partners' experiences of cancer caregiving following the patient's treatment. Studies were excluded if they focused on partners' experiences of cancer caregiving during a different phase of cancer (diagnosis, treatment, palliative care, end of life or bereavement) or included other types of caregivers.

Figure 1 shows the stages for exclusion, inclusion and purposeful sampling. Due to the focus on exploring people's lived experiences, the review aimed to provide a synthesis of qualitative studies. Quantitative studies were therefore excluded. Studies which were not

available as full text, English-language articles could not be included within the resource constraints of the review. Restricting to peer-reviewed journal articles focused the included studies on those more likely to have demonstrated an adequate degree of methodological rigour. In order to address the review aims and maintain a focus on partners' experiences after cancer treatment, studies were excluded that included participants with a different type or stage of disease, or different type of caregiver.

Table 1.1 'STARLITE' summary of search strategy

Sampling strategy	Purposeful: databases selected to sample from medicine, nursing, and social science fields, with a subset of eligible publications purposefully selected for their relevance to the review objectives
Type of study	Any type of qualitative study (included ethnographic, grounded theory, phenomenological, etc.)
Approaches	Search of electronic databases; manual search of references and citing studies, key journals, contact with experts
Range of years	From the beginning of each candidate database to the date of search (24.01.13). From the past 10 years (2003-13) for hand-search of key journals: Qualitative Health Research, volumes 13(1) – 23(7); European Journal of Cancer Care, 12(1) – 22(3); Journal of Psychosocial Oncology, 21(1) – 31(3)
Limits	English-language
Inclusion and exclusions	Inclusion: qualitative; published in a peer-reviewed journal; focus on partners' experiences of cancer caregiving post-treatment. Exclusion: not qualitative; full text not available in English in a peer-reviewed journal; not specific to cancer, or partners, or post-treatment recovery.
Terms used	S1 partner OR partners OR spous* OR husband* OR wife OR wives OR couple* OR dyad* S2 cancer NOT terminal* NOT palliative S3 qualitative OR experience* OR interview* OR (thematic analysis) OR phenomenolog* OR ethnograph* OR (grounded theory) S4 carer* OR caregiv* OR care-giv* S5 S1 AND S2 AND S3 AND S4
Electronic sources	EBSCOhost used to search: CINAHL Plus with Full Text; MEDLINE with Full Text; PsycINFO; Psychology and Behavioral Sciences Collection; Health Business Elite; Biomedical Reference Collection: Comprehensive; Library, Information Science & Technology Abstracts. Embase used to search: OVID.

Purposeful sampling

Purposeful sampling is appropriate in qualitative synthesis where the aim is interpretation and explanation rather than prediction [34]. It was adopted to maximise the quality of the synthesis within the available resources. Specifically, theory-based sampling was used to select studies that represented "important theoretical constructs about the phenomenon of interest" [38]. 10 studies (11 articles, with two separate publications from the same study

[39-40]) were purposefully sampled for providing 'information-rich' data [41] relevant to the review focus on partners' psychological adjustment post-treatment. The decision not to include a study was made on the basis of methodology, where the reporting gave insufficient detail on qualitative analysis of partners' experiences [24, 30, 42-45], or due to the topic, where there was a lack of direct relevance to psychological adjustment post-treatment [23, 46-59].

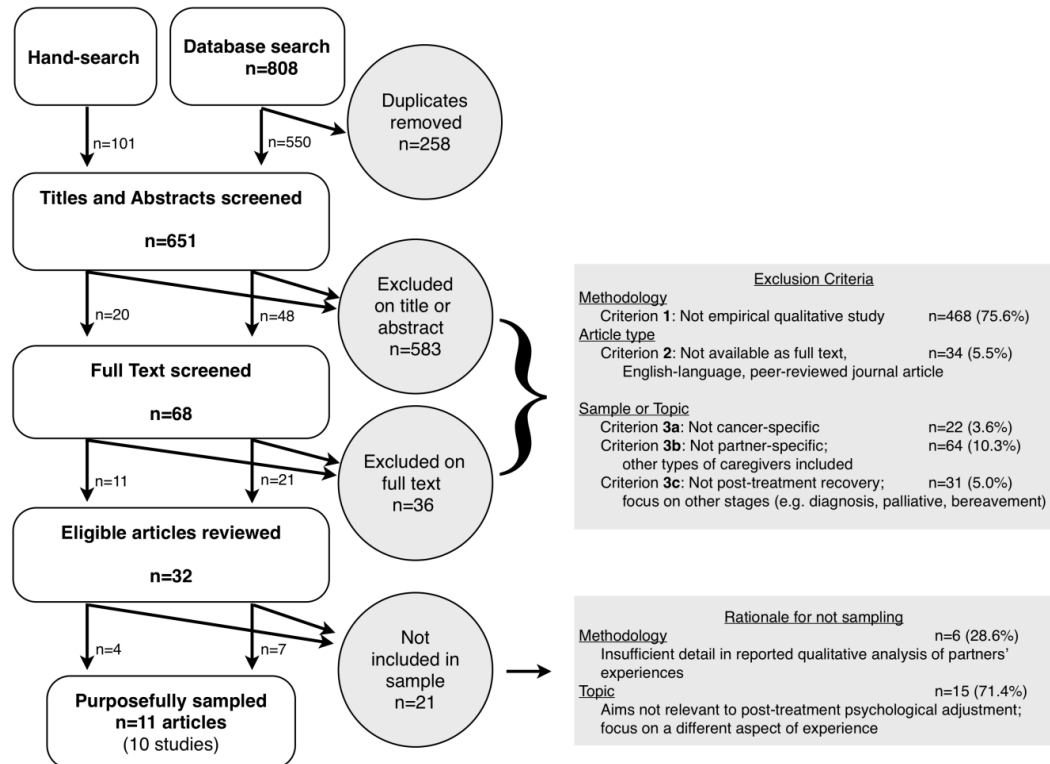


Figure 1 Flowchart of stages for exclusion, inclusion and purposeful sampling

Quality Appraisal

Quality appraisal of qualitative research remains a contentious issue, with debate over how, when or even whether to determine quality within reviews [34, 36, 60-65]. While recognising the debate, the review adopted the Critical Appraisal Skills Programme (CASP) [66] criteria as a widely-used tool, to provide a benchmark for evaluating the rigour of the included studies. The first two screening questions establish whether qualitative methodology is appropriate for the stated aims. Eight further questions address research design, recruitment, data collection and analysis, ethics, reflexivity, clarity and value of reported findings. Studies were rated on the extent to which they explicitly addressed each of these eight criteria, according to a three-point scoring system [67]. 1 point was assigned

where studies reported little or no justification or explanation of the criteria; 2 points were given if the study addressed the criteria but without full elaboration; 3 points denoted the criteria were thoroughly explained and justified. This gave a maximum total score of 24. Acknowledging that some authors do not recommend numerical scoring [65], the present review does not claim that the scores are a comprehensive or definitive measure of methodological quality. They are included (Table 1.2) to aid comparison across the studies. All papers were rated by the first author (NW). A second analyst (WB) independently coded half of the studies (n=5) and her initial ratings showed a high concordance with the first author's scores (89.2% overall, ranging from 83.3% to 95.8% across the five co-rated studies). Consensus was reached following discussion.

Data Extraction and Management

Within a systematic review, there is a risk that original study findings may be de-contextualised [34]. TAMS Analyzer software was used to keep a trail of the studies from which the different findings and themes were derived. This aided transparency, ensuring the original context of the data was retained.

Synthesis of Findings

The study findings were analysed using a Framework approach [68], a structured form of thematic analysis successfully implemented in other systematic reviews of qualitative literature [69-74]. It provided a systematic method which maintained transparency through access to original study data [75-76], with analysis grounded in study findings and guided by review aims based on prior research. Analysis followed the five step process of the Framework approach. This began with familiarisation through repeated reading and reflection on the studies. An initial thematic framework was then developed, based on key concepts identified across the dataset. This informed further organising and classifying of data. Portions of data relating to specific themes were identified and indexed, represented as codes. This data was then reorganised into thematic charts, comparing across the whole dataset whilst keeping reference to the original study and context. Finally, patterns and explanations were sought, using visual representation to develop interpretations.

In light of Fletcher *et al.*'s review [33], the initial framework was used to identify data pertaining to the patient-caregiver relationship, the cancer trajectory and contextual factors. Development of the framework incorporated these constructs identified a priori along with themes developed inductively from analysis of the studies. This iterative approach allowed

amendment and additions to the framework throughout the analytic process. It facilitated translation, forming conceptual links across the set of studies, which enabled the synthesis to 'go beyond' the primary studies, arguably a critical component of synthesis [34].

Results

Included Studies

10 studies [5, 39-40, 77-84] were included in the synthesis (with two publications from the same study analysed together; Tables 1.2 and 1.3). Sample sizes ranged from 8 to 113 (median 19), representing a total of 295 partners overall. Participants were partners of patients with various cancer types, particularly breast or prostate. Studies included female-only samples (n=3), male-only (n=3) and both genders (n=4). Overall, the majority of participants were female (78.6%). Only one study included two partners from same-sex relationships. A wide range of ages and ethnic origins were represented, although details were not always reported. Studies predominantly used semi-structured or open-ended interviews (n=8), although focus groups (n=1) and open-ended postal survey questions (n=1) were also used. Post-treatment data were collected between a few months to several years after diagnosis and treatment. A range of analytic methods was employed. The extent to which publications explicitly addressed the CASP criteria was variable, indicating moderate to high quality overall (an average score of 2 to 3 points across the criteria) for all but one study (Table 1.2).

Table 1.2 Quality appraisal ratings according to CASP criteria

Study	1 Aims	2 Method	3 Design	4 Recruitment	5 Data Collection	6 Reflexivity	7 Ethics	8 Rigour	9 Reported Findings	10 Value	Total Rating (out of 24)
1 Adams <i>et al.</i> , 2012	✓	✓	3	2	3	3	2	3	3	3	22
2 Gilbert <i>et al.</i> , 2009, 2010	✓	✓	3	3	3	1	2	3	3	3	21
3 Hoga <i>et al.</i> , 2008	✓	✓	3	2	3	1	3	3	2	3	20
4 Ka'opua <i>et al.</i> , 2007	✓	✓	2	2	3	1	1	3	3	3	18
5 Lopez <i>et al.</i> , 2012	✓	✓	3	3	3	1	2	2	2	3	19
6 Ohlsson-Nevo <i>et al.</i> , 2011	✓	✓	2	3	3	2	3	2	3	3	21
7 Persson <i>et al.</i> , 2004	✓	✓	3	2	3	1	3	2	2	3	19
8 Street <i>et al.</i> , 2010	✓	✓	1	3	3	1	2	3	2	3	18
9 Tanner <i>et al.</i> , 2011	✓	✓	2	2	2	1	2	3	2	3	17
10 Zahlis & Shands, 1993	✓	✓	1	2	3	1	1	2	2	2	14

1 point: study reported little to no justification or explanation of the criteria;

2 points: study addressed the criteria but without full elaboration;

3 points: study reported thorough explanation and justification of the criteria

Table 1.3 Study and participant characteristics

#	Study	Stated Aims	Data Collection Method and Timing	Analytic Method and Validation
1	Adams <i>et al.</i> , 2012	Experiences of cancer survivors' partners in the first 3 years post-diagnosis; use and views of primary care services' support for them as carers	Semi-structured interviews (eight conducted jointly with patient, 14 separately) 6 months to 3 years post-diagnosis	Framework analysis; Discussion between multiple analysts
2	Gilbert <i>et al.</i> , 2009, 2010	Partners' perspectives of changes and renegotiation of sexuality and intimacy post-cancer in the context of caregiving	Semi-structured interviews 12 months median length of time caring; range 6 months to 27 years.	Grounded theory; Discussion between multiple analysts, theoretical saturation
3	Hoga <i>et al.</i> , 2008	Husbands' perspectives of the effects post-mastectomy	Semi-structured interviews Timing not stated; post-mastectomy	Narrative analysis; Theoretical saturation, Researcher "communicated [main themes] to each collaborator by telephone"; discussion not explicitly reported

Table 1.3 Study and participant characteristics (Continued)

#	Study	Stated Aims	Data Collection Method and Timing	Analytic Method and Validation
4	Ka'opua <i>et al.</i> , 2007	Wives' experiences of long-term prostate cancer survivorship and use of Spiritually-Based Resources in coping and adaptation	Semi-structured interviews Held twice at 6-month intervals, 6 to 15 years since husband's initial diagnosis, with an average of 8.5 years	Combined elements of grounded theory and content analysis; Discussion between multiple analysts, member checks, triangulation
5	Lopez <i>et al.</i> , 2012	Men's experiences of caring for partners with breast and gynaecologic cancer over a 1-year period	Semi-structured interviews Conducted separately over four time periods: at beginning of treatment and at 3, 6, and 12 months	Content analysis; Discussion between multiple analysts, member checks, triangulation
6	Ohlsson-Nevo <i>et al.</i> , 2011	Patients' and partners' experiences of the first year post-surgery for colorectal cancer	Semi-structured separate interviews 1 year post-surgery	Content analysis based on the principles of Patton (2002); Discussion between multiple analysts
7	Persson <i>et al.</i> , 2004	Spouses' perceptions of living with a partner post-surgery for rectal cancer, resulting in a stoma	Focus-groups (two groups which met twice) 6 to 24 months post-surgery	Content analysis; Discussion between multiple analysts
8	Street <i>et al.</i> , 2010	Female partners' psychosocial adaptation following prostate cancer	Semi-structured interviews Conducted before treatment and 6 months later.	Not explicitly defined; fits thematic analysis, (Richards, 2005); Analysis conducted by two coders; discussion not explicitly reported
9	Tanner <i>et al.</i> , 2011	Experiences of female partners of prostate cancer survivors	Open-ended postal survey questionnaire questions Post-treatment longitudinal study over 8 years	Content analysis; Discussion between multiple analysts
10	Zahlis & Shands, 1993	Reasons men may continue to feel distress 18 months following their partners' diagnoses of breast cancer	Open-ended interview question 16-20 months post-diagnosis; 5 post-modified mastectomy, 3 post-lumpectomy	Not explicitly defined; fits thematic analysis; Two analysts independently coded; discussion not explicitly reported

Table 1.3 Study and participant characteristics (Continued)

#	Cancer Type	Sample size	Gender	Sexuality	Age (range, mean)	Ethnic Origin	Country
1	Various	22 partners	15 Female (68%), 7 Male (32%)	Not reported	n/k (4: <50; 14: 50–70; 4: >70)	20 White British, 1 White Other, 1 Black African	UK
2	Various	20 partners	13 Female (65%), 7 Male (35%)	18 heterosexual, 2 lesbian	29-76, mean: 53	18 Anglo-Australian/Anglo-Saxon, 1 Filipina, 1 Italian	Australia
3	Breast	17 partners	17 Male (100%)	Heterosexual	53-84, mean: n/k (6: 53-60y; 7: 61-70y; 3: 71-80y; 1: 81-84)	8 White (European descent), 4 Mixed race (European/African), 3 Asian, 2 African American	Brazil
4	Prostate	28 partners	28 Female (100%)	Heterosexual	55-86, mean: 73	White (28.6%), Japanese (28.6%), Chinese (21.4%), Filipina (10.7%), Native Hawaiian (10.7%)	Hawai'i, USA
5	Breast (5) Gynaecological (10)	15 partners	15 Male (100%)	Heterosexual	27-74, mean: 60	White (100%)	UK
6	Colorectal (5: Rectal, 8: Colon)	13 partners	7 Female (54%), 6 Male (46%)	Heterosexual	40–87, median: 64	Not reported; all Swedish-speakers	Sweden
7	Rectal	9 partners	6 Female (67%), 3 Male (33%)	Not reported	49-74, mean: 62	Not reported	Sweden
8	Prostate	50 partners	50 Female (100%)	Heterosexual	43-78, mean: 62	Not reported	Australia
9	Prostate	113 partners	113 Female (100%)	Heterosexual	N/k, mean: 65	White (87%), Other: not reported	USA
10	Breast	8 partners	8 male (100%)	Heterosexual	31-59, mean: n/k	Not reported	USA

Overview of Themes

The identified themes were barriers and facilitators of psychological adjustment relating to: communication and cohesion within the patient-caregiver relationship, transitions and gradual changes across the cancer trajectory, and the contextual factors of healthcare and cultural belief systems (Table 1.4).

Table 1.4 Identified barriers and facilitators of psychological adjustment

	Barriers	Facilitators
1. Patient-Caregiver Relationship		
Communication	Patient or partner reluctant to talk openly; avoidance of difficult or 'taboo' topics; attempt to protect the other or fear of causing distress Patient's emotional difficulties Partner's loneliness or isolation	Feelings or concerns openly shared Willingness to discuss or 'renegotiate' Open, honest communication Togetherness and strength in silence Communication-focused intervention
Cohesion	Stress of illness and related demands Pre-existing relationship difficulties Separation or divorce Patient perceived differently Loss of physical intimacy	Relationship perceived as closer or stronger; renewed priorities and appreciation of each other; cultivation of relationship including alternative ways of maintaining intimacy; cancer perceived as shared experience New perspective on differences; fewer quarrels Cultural or religious beliefs about marriage and commitment
2. Cancer Trajectory		
Transitions	Unprepared or anxious about caregiving Difficult initial emotional impact Disruption to roles or routines Sudden unanticipated changes Grieving current or future losses (of sexual functioning, work, retirement plans, social life) Fear of recurrence	Support from family Support from healthcare team Health-promoting behaviours Healthy lifestyle changes Satisfaction over caregiving
Gradual Changes	Cumulative exhaustion On-going caregiving demands Persistent worries, especially if unshared Increasing loneliness or isolation Increasing tension in relationship Need for continuing support	Patient's gradual physical recovery Acceptance Reflection and reappraisal Spirituality Perceived growth as individual or couple; learning from adversity; reconnecting with priorities or values

Table 1.4 Identified barriers and facilitators of psychological adjustment (Continued)

3. Contextual Factors		
Healthcare System	Partners not acknowledged or involved in patient's healthcare Partners' needs, including health problems, not addressed; partner ensuring healthcare team prioritises patient needs above their own Impact of patient confidentiality on information sharing and doctor-caregiver relationship Lack of information or preparation prior to discharge from hospital; lack of follow up; failure to address sensitive topics (e.g. sex, spirituality)	Proactive approach Healthcare teams involving partners and developing a working relationship with them Practical support Emotional support Informational support Early intervention Counselling or psychology input Challenging cultural assumptions, permission-giving
Culture & Belief Systems	Gender norms contributing to emotional difficulty over caregiving tasks and role changes Perceived expectations of caregiving role, e.g. as an obligation not a choice Culture-bound beliefs about sex impeding adaptation to change in physical relationship Partner's perceived duty to subordinate own needs	Spiritual or religious beliefs perceived as source of strength Acceptance and growth Reappraisal of circumstances to find meaning, hope, purpose Shared means of coping with adversity Connectedness Community

Patient-Caregiver Relationship

Communication

Communication difficulties were a barrier to successful adjustment, with a number of underlying causes [5, 39-40, 80-84]. Some studies found that partners perceived the patient was reluctant to talk openly with them [80-81, 83-84]. This was associated with patients' emotional difficulties in some instances [80-81, 83-84] or interpreted as the patient's attempt to protect his or her partner [81]. The reverse was also described, where the partner was reluctant to speak openly, for fear of causing the patient additional distress [5, 83]. On both sides, avoidance of difficult or 'taboo' topics contributed to communication difficulties, compounding partners' sense of loneliness and isolation, with a detrimental impact on the quality of their relationship and their psychological adjustment [39-40, 80-81, 83-84].

Adjustment was helped by good communication [40, 78, 80, 82], and two studies suggested the potential benefit of interventions to enhance couples' communication [82-83]. Generally,

sharing feelings or concerns openly, and willingness to discuss or 'renegotiate', were described as helpful. For example, some couples viewed open, honest communication as crucial in adjusting to changes in physical intimacy and sex [40]. However, one study reported that some couples found 'togetherness and strength in silence' [80].

Cohesion

Loss of cohesion in the relationship was a source of difficulty and distress [5, 39, 78-84]. The stress of illness and related demands, particularly in the context of pre-existing relationship difficulties, could lead to growing isolation [39-40, 82]. In some cases, it resulted in separation or divorce [77, 84]. Some studies found that partners perceived the patient differently after diagnosis and treatment, particularly associated with cognitive decline, emotional difficulties or marked physical impairment or changes, such as a stoma [39-40, 81, 83]. Also, where caregiving involved supporting the patient with personal care, this could sometimes result in the partner seeing the patient more as an invalid or child, contributing to disruption of their sexual relationship [39-40]. Loss of physical intimacy was distressing in itself but could also have a broader impact on couples' relationships, contributing to communication difficulties and loss of closeness [80, 81, 84], difficult emotions such as frustration, guilt, sadness or grief [39-40, 78, 81, 83-84], and disrupting couples' plans to have children together in the future [39-40].

By contrast, a theme of increased cohesion recurred in six studies [40, 77-78, 80, 82-83] with partners reported to view their relationship as closer or stronger following their experiences with cancer. This was related to a fresh appreciation of their partners [77-78] and renewed sense of priorities [83], enabling them to let go of trivial differences [82] and preventing quarrels [80]. Having been confronted with mortality, determination to make the most of their time together motivated the cultivation of their relationship [78]. Even negative changes such as loss of their pre-illness sexual relationship could precipitate a renewed effort to find alternative ways of maintaining closeness [40]. Four studies noted that cancer was perceived as a shared experience [5, 77, 78, 82], with one describing how partners used 'we', 'us' and 'our' to articulate their experiences of cancer [82]. Growing cohesion was related to good communication [82] and to cultural or religious beliefs about marriage and commitment [77-78].

Trajectory

Transition period

Adjustment difficulties around transitions were commonly referred to in the study findings [5, 39-40, 78-83]. Adjustment after bringing the patient home from hospital was more difficult where the partner felt unprepared and anxious about caregiving tasks [79]. Even where later acceptance and successful coping were described, there was acknowledgement of the difficult emotional impact initially [5, 77, 78, 82]. Transition to the post-treatment phase was marked by disruption to roles and routines [5, 39-40, 77, 79-83]. Some difficulties were related to temporary changes in the initial period following treatment which resolved with time and the patient's physical recovery [81]. However, some difficulties related to sudden changes which were long-term or permanent and involved grieving for current and future losses [39-40, 80-84], such as loss of sexual functioning [39-40, 77-78, 80-84] and loss of work [5, 83] or retirement plans [80]. A common feature of the post-treatment phase was partners' fear of recurrence [5, 77, 79-84], which could be affected by communication with the patient regarding these worries [80] or with the healthcare team regarding prognosis [5, 84].

Support from family and the healthcare team helped couples manage the transition following treatment [77, 79]. This phase sometimes precipitated health-promoting behaviours and lifestyle changes for partners and patients, described as a source of satisfaction for partners [79] and helpful for the adaptation process [5, 78, 81-83].

Gradual changes

Some of the reported barriers to psychological adjustment related to gradual changes taking effect later in the post-treatment phase [39-40, 79-84], such as the cumulative exhaustion associated with on-going caregiving demands [39-40], the impact of 'gnawing worries' which, if unshared, could lead to a growing sense of loneliness and isolation for the partner [80] and contribute to growing tensions within the relationship [84]. Disappointment, frustration and other emotional difficulties could arise when the reality of lasting changes to their relationship or lifestyle began to be fully realised [81-83] with recognition of the need for continuing support [79].

However, much of what was described as helpful to psychological adjustment also occurred gradually over time. While the patient's gradual physical recovery is important, it may be neither sufficient nor necessary for their own or their partner's successful psychological

adjustment [80]. Acceptance was a key theme reflected in most studies [39-40, 77-83], involving a process of reflection and reappraisal. Spirituality was an important related factor [77-78, 80, 83]. Reported themes included learning from adversity, perceiving experiences of cancer as an opportunity to reconnect with core priorities and values [78, 81-82], growing individually and as a couple [78, 83].

Context

Healthcare system

Failure to acknowledge or involve partners or address their needs formed barriers to successful adjustment [5, 39-40, 77-78, 80-81]. These needs included partners' own health problems [5, 78, 80, 83]. However, one study highlighted that some partners actively sought to ensure that healthcare professionals prioritised patients over themselves [79]. It was noted that partners are more likely to accept support or intervention from services where it is perceived to assist them in providing care, and where it is perceived not to jeopardise resources for the patient. The study discussed how patient confidentiality affected sharing of information and the doctor-caregiver relationship. Further problems included lack of adequate information and preparation prior to discharge from hospital and inadequate follow up [5, 81], as well as failure to ask about important but sensitive topics like sex [39-40, 78] or spirituality [77-78].

There were some positive accounts of partners' experiences with the healthcare system [77, 81, 83]. However, much of what was discussed as facilitating psychological adjustment did not pertain to partners' experiences of existing practice but rather to proposed improvements [5, 39-40, 77-84]. It was suggested that couples would benefit from a proactive approach [5, 78, 84], seeking to involve partners and develop a relationship with the family [5, 77, 80, 81, 83]. Providing practical and emotional support was encouraged, highlighting the importance of information, advice and preparation as well as asking, listening and normalising [77-79, 81-83]. Early intervention was advised [84], with referral to counselling or psychology input where necessary [82]. Healthcare professionals were encouraged to fulfil their role in challenging cultural assumptions and in giving caregivers permission to address their own needs where appropriate [39-40], guiding people towards more adaptive coping [82].

Culture and belief systems

Certain personal and culture-bound beliefs were found to be unhelpful for adjusting to caregiving. For instance, gender norms could create considerable tensions relating to

caregiving tasks and role changes, found in studies across different cultural contexts [39-40, 79-82]. Perceived expectations of the caregiving role could place pressure on partners [39-40, 82]. Viewing caregiving as an obligation, rather than a choice, was associated with poorer psychological adjustment including loneliness, anger, resentment and guilt [39-40, 79-82]. Culture-bound beliefs about sex could hinder successful renegotiation of physical intimacy [40]. Across various contexts, studies described partners subordinating their own healthcare, social, sexual or other general needs [5, 39-40, 78-79].

Conversely, beliefs and cultural factors could also serve as a significant resource, as emphasised by four studies [77, 78, 80, 83]. Spiritual or religious beliefs fostered acceptance and growth and constituted a source of strength for some, helping them to reappraise their circumstances and find meaning, hope and purpose [77, 78, 80, 83]. Cultural practices could also enable a shared coping and deepening of the couple's relationship and connectedness [78, 83].

Discussion

Clinical Implications

The identified themes highlight barriers and facilitators of psychological adjustment, helping to identify partners at risk of poor outcomes who may benefit from additional support or sign-posting to relevant resources. In light of the findings on communication, it may be helpful to explore underlying reasons for both patients' and partners' reluctance to discuss certain issues. This requires sensitivity to the possibility that it is indicative of broader emotional difficulties, or an attempt to protect the other, or linked to pre-existing relationship difficulties. Two notable sub-themes were the potentially 'taboo' subjects of sex and spirituality, which were said to be neglected issues within routine clinical practice [39-40, 77-78]. Although two studies suggested communication-focused intervention could be helpful [82-83], further evidence is required on specifically how healthcare professionals can promote good communication in practice. Negative case analysis highlighted the contrasting relational style of 'togetherness in silence', which indicates the need to be mindful of individual differences in communication patterns. Some couples may prefer times of mutually-acceptable silence rather than open discussion [80].

To foster cohesion and adjustment, services can help couples to frame the illness as a shared experience. For instance, healthcare professionals can explicitly invite a patient to bring the partner to appointments and discuss coping with cancer as a couple. The theme of increased

cohesion following cancer supports the idea of illness exerting a 'centripetal' force on families, initially drawing them together [85]. This initial 'rallying round' can occur within the couple, their wider social support network, and the healthcare system. Healthcare professionals may be able to make use of this by incorporating the wider network into post-treatment plans such as the 'recovery package' initiative [86]. For example, in research on Survivorship Care Planning, patients stated their preference for the document to be shared with family members [87]. Such preparation can be valuable to partners facing lifestyle changes and unfamiliar roles. Adjustment may be facilitated by helping couples maintain a degree of normalcy and supporting them to negotiate new roles and routines, being available to help resolve early difficulties during the transition period.

From transitions to more gradual changes, the issue of timing is relevant to the way in which input is delivered. For example, caregivers' information needs have been highlighted [5, 77-83]. However, if a healthcare professional takes the expert role and tells caregivers what they should be doing, providing a mass of information at a time of transition and upheaval, they risk leaving the caregiver feeling overwhelmed [88]. This can inadvertently increase caregivers' sense of burden, associated with poorer psychological adjustment [89]. By contrast, well-paced information, tailored to the individual's needs and offered in a timely and collaborative manner, can develop their sense of self-efficacy and promote successful adjustment [90].

Healthcare professionals have a role in directing couples or families towards relevant sources of support for the longer term. In doing so, they can provide the 'permission' to access these services after treatment. This may be the very time when additional emotional support is most helpful, particularly if there is diminishing input from other healthcare services or the wider network. Healthcare professionals should be alert to the risk of partners' cumulative physical exhaustion or growing tensions in their relationship. However, some important facilitators of psychological adjustment can also develop gradually over time. For instance, reappraisal can lead to acceptance as well as adaptive changes [82]. This indicates the potential benefit of related interventions such as Acceptance and Commitment Therapy and Mindfulness for this population [91-92].

Culture and belief systems can be deeply valuable resources to draw upon and are often described as supporting people through their experiences with cancer [77-78, 80, 83]. There may be benefit to initiating conversations about reconnecting and making use of community

support, including their spiritual or religious community where relevant. However, it is also important to be aware of culturally-bound beliefs which can constitute entrenched barriers to adjustment. For partners who hold the belief that addressing their own needs is not appropriate or fair on the patient, this may inhibit help-seeking behaviour and access of support.

To address the reality of healthcare needs in the context of cancer survivorship, service design should take a broad and long-term perspective. The healthcare system risks overlooking caregivers' own health and broader needs [5-6], reinforcing unhelpful cultural messages about what is expected or acceptable. This can contribute to caregivers' experiences of isolation or obligation. By contrast, healthcare teams have the opportunity to foster connectedness and good communication with the family over the long-term. This can include initiating helpful conversations, encouraging self-care as well as challenging myths, taboos and unhelpful beliefs [5, 39-40, 77-78, 80, 83].

Limitations

A vast evidence-base on cancer caregiving has accumulated [33] and qualitative research has typically been poorly-indexed [36]. While endeavouring to conduct a broad search, the methods may therefore have failed to identify relevant studies. Figure 1 illustrates the importance of manual searching, given the comparatively high proportion of relevant studies identified by the hand-search. Evidently, there remains the need to improve indexing of qualitative research. The review may also have been limited by excluding studies that appeared relevant in topic but whose sample included one caregiver who was not a partner [93] or a non-malignant diagnosis [27]. Additional search terms and inclusion of other types of publications or languages may yield further relevant data. The first author's perspective and prior assumptions inevitably influenced the interpretation and synthesis. However, the framework provided an intentional, transparent use of prior conceptualisations to pursue fruitful avenues for further exploration. The iterative approach returned to the text of the primary studies throughout the analytic process.

Appraisal of the reviewed studies according to the CASP criteria indicated the studies were predominantly of moderate to high quality. This would be anticipated given the use of purposeful sampling. However, there was a notable lack of reflexivity reported in all but two of the publications (Table 1.2), compromising the transparency of authors' impact on findings. Nonetheless, it is difficult to distinguish between quality of the reporting from

quality of the study itself. This supports the role of reporting guidelines such as the consolidated criteria for reporting qualitative research (COREQ) [94]. Although no formal sensitivity analysis was conducted [95], it was noted that the study with the lowest CASP rating [84] (Table 1.2) contributed minimally to the review themes (Appendix 2). This is congruent with other findings that poorer quality studies contribute less to the synthesis [34].

Future Research

Future studies could seek to recruit partners directly and purposefully sample those with relationship difficulties or who have separated. It was suggested that it would be useful to include both patients and their partners to compare their perspectives [39]. Several studies suggested including more couples from ethnic minorities, lower socio-economic status, and same-sex relationships [5, 39-40, 78, 83]. Since the studies were predominantly from Western, individualistic contexts, it could be useful to recruit more participants from collectivist cultures given the findings on cohesion and culture [96-98]. Topics for future research include risk factors for loss of cohesion and relationship breakdown post-treatment, interventions to improve couples' communication and cohesion, and family involvement in survivorship care-plans. Comparing experiences of those who are single or establishing new relationships post-treatment would also broaden the evidence-base. Further comparison with other stages and transitions could inform service delivery throughout the cancer journey.

Conclusions

The reviewed studies underscore the importance of the patient-caregiver relationship across the cancer trajectory and within the wider context. Partners' adjustment can be helped or hindered by issues around communication and cohesion, transitions and gradual changes, as well as healthcare and cultural systems. Future research should explore ways of promoting a proactive, systemic approach to clinical practice, to facilitate long-term adjustment for couples.

References

1. Office for National Statistics. *Cancer incidence and mortality in the United Kingdom, 2008-10*. Office for National Statistics: London, 2012.
2. Bevans M, Stenberg E. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA: The Journal of the American Medical Association* 2012; **307**:398-403.
3. Lambert S D, Harrison J D, Smith E, Bonevski B, Carey M, Laws C *et al*. The unmet needs of partners and caregivers of adults diagnosed with cancer: A systematic review. *BMJ Supportive & Palliative Care* 2012; **2**:224-230.
4. Northouse L L, Schafer J A, Tipton J, Metivier L. The concerns of patients and spouses after the diagnosis of colon cancer: A qualitative analysis. *Journal of Wound, Ostomy and Continence Nursing* 1999; **26**:8-17.
5. Adams E, Boulton M, Rose P, Lund S, Richardson A, Wilson S *et al*. A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care. *Supportive Care in Cancer* 2012; **20**:2785-2794.
6. Sinfield P, Baker R, Ali S, Richardson A. The needs of carers of men with prostate cancer and barriers and enablers to meeting them: A qualitative study in England. *European Journal of Cancer Care* 2012; **21**:527-534.
7. Bevans M, Wehrle L, Prachenko O, Soeken K, Zabora J, Wallen G. Distress screening in allogeneic hematopoietic stem cell (HSCT) caregivers and patients. *Psycho-Oncology* 2011; **20**:615-622.
8. Harrison S, Watson E, Ward A, Khan N, Turner D, Adams E *et al*. Cancer survivors' experiences of discharge from hospital follow-up. *European Journal of Cancer Care* 2012; **21**:390-397.
9. Girgis A, Lambert S D, Mcelduff P, Bonevski B, Lecathelinais C, Boyes A *et al*. Some things change, some things stay the same: A longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psycho-Oncology* 2013; **22**:1557-1564.
10. Given B A, Given C W, Sherwood P R. Family and caregiver needs over the course of the cancer trajectory. *The Journal of Supportive Oncology* 2012; **10**:57-64.
11. Given B, Sherwood P, Given C. Support for caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiology, Biomarkers & Prevention* 2011; **20**:2015-2021.
12. Li Q, Mak Y, Loke A. Spouses' experience of caregiving for cancer patients: A literature review. *International Nursing Review* 2012; **60**: 178-187.
13. Stenberg U, Ruland C, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology* 2010; **19**:1013-1025.
14. Buckner L, Yeandle S. *Valuing carers 2011; Calculating the value of carers' support*. Carers UK: London, 2011.
15. Blum K, Sherman D. Understanding the experience of caregivers: A focus on transitions. *Seminars in Oncology Nursing* 2010; **26**:243-258.
16. Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives. *European Journal of Cancer* 2003; **39**:1517-1524.
17. Northouse L L. Helping families of patients with cancer. *Oncology Nursing Forum* 2005; **32**:743-750.
18. Olson R. *Carers of cancer patients: Understanding their support service needs*. Cancer Council ACT: Acton ACT, 2009.
19. Segrin C, Badger T, Harrington J. Interdependent psychological quality of life in dyads adjusting to prostate cancer. *Health Psychology* 2012; **31**:70-79.
20. Morgan M A, Small B J, Donovan K A, Overcash J, Mcmillan S. Cancer patients with pain: The spouse/partner relationship and quality of life. *Cancer Nursing* 2011; **34**:13-23.

21. Green J, Thorogood N. *Qualitative Methods for Health Research*. (2nd ed.) Sage Publications: London, 2004.
22. Pope C, Mays N. *Qualitative research in health care*. (3rd ed.) Blackwell Publishing: Oxford, 2006.
23. Kidd L, Forbat L, Kochen M, Kearney N. The supportive care needs of carers of people affected by cancer stationed in British Forces Germany. *European Journal of Cancer Care (England)* 2011; **20**:212-219.
24. Maughan K, Heyman B, Matthews M. In the shadow of risk: How men cope with a partner's gynaecological cancer. *International Journal of Nursing Studies* 2002; **39**:27-34.
25. Northouse L, Williams A, Given B, Mccorkle R. Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology* 2012; **30**:1227-1234.
26. Röing M, Hirsch J M, Holmström I. Living in a state of suspension—a phenomenological approach to the spouse's experience of oral cancer. *Scandinavian Journal of Caring Sciences* 2008; **22**:40-47.
27. Sabo B, Mcleod D, Couban S. The experience of caring for a spouse undergoing hematopoietic stem cell transplantation: Opening Pandora's box. *Cancer Nursing* 2013; **36**:29-40.
28. Sandén I, Söderhamn O. Experiences of living in a disrupted situation as partner to a man with testicular cancer. *American Journal of Men's Health* 2009; **3**:126-133.
29. Sherwood P, Hricik A, Donovan H, Bradley S E, Given B A, Bender C M *et al*. Changes in caregiver perceptions over time in response to providing care for a loved one with a primary malignant brain tumor. *Oncology Nursing Forum* 2011; **38**:149-155.
30. Hodgkinson K, Butow P, Hobbs K M, Wain G. After cancer: The unmet supportive care needs of survivors and their partners. *Journal of Psychosocial Oncology* 2007; **25**:89-104.
31. Kim Y, Spillers R, Hall D. Quality of life of family caregivers 5 years after a relative's cancer diagnosis: Follow-up of the national quality of life survey for caregivers. *Psycho-Oncology* 2012; **21**:273-281.
32. Lewis F M. The effects of cancer survivorship on families and caregivers: More research is needed on long-term survivors. *The American Journal of Nursing* 2006; **106**:26.
33. Fletcher B, Miaskowski C, Given B, Schumacher K. The cancer family caregiving experience: An updated and expanded conceptual model. *European Journal of Oncology Nursing* 2012; **16**:387-398.
34. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology* 2008; **8**:45-55.
35. Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: Reviewing disparate data systematically. *Qualitative Health Research* 2002; **12**:1284-1299.
36. Petticrew M, Roberts H. *Systematic reviews in the social sciences: A practical guide*. (1st ed.) Blackwell Publishing: Oxford, 2006.
37. Booth A. "Brimful of starlite": Toward standards for reporting literature searches. *Journal of the Medical Library Association* 2006; **94**:421-429.
38. Suri H. Purposeful sampling in qualitative research synthesis. *Qualitative Research Journal* 2011; **11**:70.
39. Gilbert E, Ussher J M, Hawkins Y. Accounts of disruptions to sexuality following cancer: The perspective of informal carers who are partners of a person with cancer. *Health* 2009; **13**:523-541.
40. Gilbert E, Ussher J M, Perz J. Renegotiating sexuality and intimacy in the context of cancer: The experiences of carers. *Archives of Sexual Behavior* 2010; **39**:998-1009.
41. Patton M Q. *Qualitative research and evaluation methods*. (3rd ed.) Sage Publications: Thousand Oaks, 2002.
42. Hodgson T. Oesophageal cancer: Experiences of patients and their partners. *British Journal of Nursing* 2006; 1157-1160.

43. Green H, Wells D, Laakso L. Coping in men with prostate cancer and their partners: A quantitative and qualitative study. *European Journal of Cancer Care (England)* 2011; **20**:237-247.
44. Bishop M, Curbow B, Springer S, Lee J, Wingard J. Comparison of lasting life changes after cancer and BMT: Perspectives of long-term survivors and spouses. *Acta Oncologica* 2011; **20**:926-934.
45. Sanders S, Pedro L W, Bantum E O C, Galbraith M E. Couples surviving prostate cancer: Long-term intimacy needs and concerns following treatment. *Clinical Journal of Oncology Nursing* 2006; **10**:503-508.
46. Fillion L, De Serres M, Lapointe-Goupil R, Bairati I, Gagnon P, Deschamps M *et al.* Implementing the role of patient-navigator nurse at a university hospital centre. *Canadian Oncology Nursing Journal* 2006; **16**:5-10.
47. Bruun P, Pedersen B D, Osther P J, Wagner L. The lonely female partner: A central aspect of prostate cancer. *Urologic Nursing* 2011; **31**:294-299.
48. Rusinak R L, Murphy J F. Elderly spousal caregivers: Knowledge of cancer care, perceptions of preparedness, and coping strategies. *Journal of Gerontological Nursing* 1995; **21**:33-41.
49. Cagle C S, Wells J N. Healthcare literacy. *Clinical Journal of Oncology Nursing* 2010; **14**:E1-E9.
50. BurrIDGE L, Mitchell G, Jiwa M, Girgis A. Consultation etiquette in general practice: A qualitative study of what makes it different for lay cancer caregivers. *BMC Family Practice* 2011; **12**:110-118.
51. Céilleachair A, Costello L, Finn C, Timmons A, Fitzpatrick P, Kapur K *et al.* Inter-relationships between the economic and emotional consequences of colorectal cancer for patients and their families: A qualitative study. *BMC Gastroenterology* 2012; **12**:62-72.
52. Trudeau-Hern S, Daneshpour M. Cancer's impact on spousal caregiver health: A qualitative analysis in grounded theory. *Contemporary Family Therapy* 2012; **34**:534-554.
53. Ussher J M, Perz J. Gender differences in self-silencing and psychological distress in informal cancer carers. *Psychology of Women Quarterly* 2010; **34**:228-242.
54. Lohfeld L, Brazil K, Willison K. Continuity of care for advanced cancer patients: Comparing the views of spousal caregivers in Ontario, Canada, to Dumont *et al.*'s theoretical model. *Journal of Palliative Care* 2007; **23**: 117-126.
55. Schumacher K L, Stewart B J, Archbold P G, Dodd M J, Dibble S L. Family caregiving skill: Development of the concept. *Research in Nursing & Health* 2000; **23**:191-203.
56. Finocchiaro C, Botturi A, Lamperti E, Gauri S, Petrucci A, Simonetti G *et al.* Privacy-Solidarity conflict: The communication with the support group. *Neurological Sciences* 2011; **32**:225-227.
57. Morton K, Goodacre L. An exploration of the impact of home enteral tube feeding on the eating habits of the partners of adults receiving home enteral tube feeding. *Journal of Human Nutrition and Dietetics* 2008; **21**:397-397.
58. Swanberg J E. Making it work: Informal caregiving, cancer, and employment. *Journal of Psychosocial Oncology* 2006; **24**:1-18.
59. Nanton V, Docherty A, Meystre C, Dale J. Finding a pathway: Information and uncertainty along the prostate cancer patient journey. *British Journal of Health Psychology* 2009; **14**:437-458.
60. Booth A. *Cochrane or cock-eyed? How should we conduct systematic reviews of qualitative research?* Proceedings from Qualitative Evidence-Based Practice Conference: Coventry, 2001.
61. Chung C, Hwang E. Couples' experiences of breast cancer in Korea: A descriptive qualitative study. *Cancer Nursing* 2012; **35**:211-220.
62. Dixon-Woods M, Bonas S, Booth A, Jones D R, Miller T, Sutton A J *et al.* How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative*

- Research* 2006; **6**:27-44.
63. Dixon-Woods M. Using framework-based synthesis for conducting reviews of qualitative studies. *BMC Medicine* 2011; **9**:39-40.
 64. Walsh D, Downe S. Meta-Synthesis method for qualitative research: A literature review. *Journal of Advanced Nursing* 2005; **50**:204-211.
 65. Walsh D, Downe S. Appraising the quality of qualitative research. *Midwifery* 2006; **22**:108-119.
 66. Public Health Research Unit. *Critical appraisal skills programme (CASP) 10 questions to help you make sense of qualitative research*. Public Health Research Unit: London, 2002.
 67. Duggleby W, Holtslander L, Kylma J, Duncan V, Hammond C, Williams A. Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research* 2010; **20**:148-158.
 68. Ritchie J, Lewis J. *Qualitative research practice: A guide for social science students and researchers*. (1st ed.) Sage Publications: London, 2003.
 69. Brunton G, Oliver S, Oliver K, Lorenc T. A synthesis of research addressing children's young people's and parents' views of walking and cycling for transport. 2006;
 70. Carroll C, Booth A, Cooper K. A worked example of "best fit" framework synthesis: A systematic review of views concerning the taking of some potential chemopreventive agents. *BMC Medical Research Methodology* 2011; **11**:29-38.
 71. Jones M L. Role development and effective practice in specialist and advanced practice roles in acute hospital settings: Systematic review and meta-synthesis. *Journal of Advanced Nursing* 2005; **49**:191-209.
 72. Oliver S, Harden A, Rees R, Shepherd J, Brunton G, Garcia J *et al*. An emerging framework for including different types of evidence in systematic reviews for public policy. *Evaluation* 2005; **11**:428-446.
 73. Oliver S R, Rees R W, Clarke-Jones L, Milne R, Oakley A R, Gabbay J *et al*. A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expectations* 2008; **11**:72-84.
 74. Seymour K C, Addington-Hall J, Lucassen A M, Foster C L. What facilitates or impedes family communication following genetic testing for cancer risk? A systematic review and meta-synthesis of primary qualitative research. *Journal of Genetic Counseling* 2010; **19**:330-342.
 75. Jones M L. Application of systematic review methods to qualitative research: Practical issues. *Journal of Advanced Nursing* 2004; **48**:271-278.
 76. Dixon-Woods M, Shaw R L, Agarwal S, Smith J A. The problem of appraising qualitative research. *Quality and Safety in Health Care* 2004; **13**:223-225.
 77. Hoga L, Mello D, Dias A. Psychosocial perspectives of the partners of breast cancer patients treated with a mastectomy: An analysis of personal narratives. *Cancer Nursing* 2008; **31**:318-325.
 78. Ka'Opua L S I, Gotay C C, Boehm P S. Spiritually based resources in adaptation to long-term prostate cancer survival: Perspectives of elderly wives. *Health & Social Work* 2007; **32**:29-39.
 79. Lopez V, Copp G, Molassiotis A. Male caregivers of patients with breast and gynecologic cancer: Experiences from caring for their spouses and partners. *Cancer Nursing* 2012; **35**:402-10.
 80. Ohlsson-Nevo E, Andershed B, Nilsson U, Anderzén-Carlsson A. Life is back to normal and yet not—partners' and patient's experiences of life of the first year after colorectal cancer surgery. *Journal of Clinical Nursing* 2011; **21**:555-563.
 81. Persson E, Severinsson E, Hellström A L. Spouses' perceptions of and reactions to living with a partner who has undergone surgery for rectal cancer resulting in a stoma. *Cancer Nursing* 2004; **27**:85-90.
 82. Street A, Couper J, Love A, Bloch S, Kissane D, Street B. Psychosocial adaptation in

- female partners of men with prostate cancer. *European Journal of Cancer Care (England)* 2010; **19**:234-242.
83. Tanner T, Galbraith M, Hays L. From a woman's perspective: Life as a partner of a prostate cancer survivor. *Journal of Midwifery & Womens Health* 2011; **56**:154-160.
 84. Zahlis E H, Shands M E. The impact of breast cancer on the partner 18 months after diagnosis. *Seminars in Oncology Nursing* 1993; **9**:83-87.
 85. Rolland J S. Chronic illness and the life cycle: A conceptual framework. *Family Process* 1987; **26**:203-221.
 86. Department of Health. *Living with & beyond cancer: Taking action to improve outcomes (an update to the 2010 the national cancer survivorship initiative vision)*. Department of Health: London, 2013.
 87. Mayer D K, Gerstel A, Leak A N, Smith S K. Patient and provider preferences for survivorship care plans. *Journal of Oncology Practice* 2012; **8**:e80-e86.
 88. Whyte F, Smith L. A literature review of adolescence and cancer. *European Journal of Cancer Care* 1997; **6**:137-146.
 89. Gaugler J E, Linder J, Given C W, Kataria R, Tucker G, Regine W F. Family cancer caregiving and negative outcomes: The direct and mediational effects of psychosocial resources. *Journal of Family Nursing* 2009; **15**:417-444.
 90. Hudson P, Aranda S, McMurray N. Intervention development for enhanced lay palliative caregiver support—the use of focus groups. *European Journal of Cancer Care* 2002; **11**:262-270.
 91. Birnie K, Garland S N, Carlson L E. Psychological benefits for cancer patients and their partners participating in mindfulness-based stress reduction (MBSR). *Psycho-Oncology* 2010; **19**:1004-1009.
 92. Karekla M, Constantinou M. Religious coping and cancer: Proposing an acceptance and commitment therapy approach. *Cognitive and Behavioral Practice* 2010; **17**:371-381.
 93. Lethborg C E, Kissane D, Burns W I. 'It's not the easy part': The experience of significant others of women with early stage breast cancer, at treatment completion. *Social Work in Health Care* 2003; **37**:63-85.
 94. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007; **19**:349-357.
 95. Dixon-Woods M, Sutton A, Shaw R, Miller T, Smith J, Young B *et al*. Appraising qualitative research for inclusion in systematic reviews: A quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy* 2007; **12**:42-47.
 96. Centre for Research and Dissemination. *Systematic reviews: CRD's guidance for undertaking reviews in health care*. Centre for Research and Dissemination: York, 2009.
 97. Hou W K, Lam W W T, Fielding R. Adaptation process and psychosocial resources of Chinese colorectal cancer patients undergoing adjuvant treatment: A qualitative analysis. *Psycho-Oncology* 2009; **18**:936-944.
 98. Lee J, Bell K. The impact of cancer on family relationships among Chinese patients. *Journal of Transcultural Nursing* 2011; **22**:225-234.

Thesis Study Aims

The systematic review in the previous chapter highlights the importance of the patient-caregiver relationship, the post-treatment transition period through to longer-term adjustment, and contextual factors including interactions with healthcare services. The present study sought to provide a more detailed analysis of patient-caregiver dyads, a gap identified in recent research (Beattie & Lebel, 2011; Fletcher *et al.*, 2012; Hagedoorn *et al.*, 2011; Mellon *et al.*, 2006, 2007; Waldron *et al.*, 2012). It therefore included both cancer survivors and their caregivers, as suggested by one of the reviewed studies and echoed in other literature (Mellon *et al.*, 2006). The focus was on the period after completion of treatment, which is noted to be a key transition period (Murray *et al.*, 2010). While colorectal (bowel) cancer is the third most common type of cancer within the UK, it remains less well-researched than prostate or breast cancer (Hopkinson *et al.*, 2012). It is increasing in incidence (Office for National Statistics, 2012) but also has increasing survival rates with early detection (Cancer Research UK, 2011). Recovery from colorectal cancer can require considerable post-treatment care at home, affecting partners as well as patients (Denlinger & Barsevick, 2009; Jansen *et al.*, 2010). The study therefore aimed to explore couples' experiences of colorectal cancer services from the perspectives of both patients and their partners, focusing on the transition period after treatment.

Journal Article

Formatting for the Journal Article adheres to the author guidelines issued by the Journal of Cancer Survivorship (Appendix 14), except where these conflict with the University of Edinburgh regulatory standards for the thesis format.

Title

Shared recovery: Couples' experiences after treatment for colorectal cancer

Authors

Naomi White, ^{1, 2}

Emily Newman, ¹

Margaret Mclean, ²

¹School of Health in Social Science, University of Edinburgh, UK

²NHS Grampian, Aberdeen, UK

Corresponding author's details

Naomi White, Roxburghe House, Ashgrove Road, Aberdeen AB25 3BX.

Email: naomi.white@nhs.net

Telephone: 01224 557 080

Abstract

Purpose: To explore couples' experiences of colorectal cancer services from the perspectives of cancer survivors and their partners, focusing on the transition to survivorship.

Methods: Separate, semi-structured interviews were conducted with a purposeful sample of 10 participants, comprising five patient-partner dyads. Data were analysed using the Framework approach, incorporating dyadic analysis to compare narratives within as well as between couples.

Results: Three overarching themes were identified: recovery, relationship dynamics, and healthcare services. Cancer was viewed as a shared experience and reciprocal influence was evident in couples' experiences. Stoicism was a common response but sometimes impeded sharing concerns or accessing support. Some participants reported good support from healthcare services throughout, while others described times of feeling let down and deserted.

Conclusions: The impact of cancer can endure beyond the completion of treatment for survivors as well as their partners. The findings underscore the value of a systemic approach for supporting couples during recovery from colorectal cancer, and demonstrate the need for greater consistency of positive practice across the cancer trajectory.

Keywords: *colorectal cancer, caregivers, survivorship, qualitative, health care*

Implications for Cancer Survivors: Transition to survivorship involves a recovery process that can be affected by relationships between survivors and their partners, as well as between couples and healthcare services. The study highlights the impact of communication and coping styles on access of support by survivors and caregivers.

Introduction

"In clinical terms, at least, I was cancer free and [the surgeon] said, 'Well, I don't think I need see you for a month.' It was the sentence I'd been waiting to hear ever since I so pointedly didn't hear it after the first lot of radiation back in May. I should have whooped with delight. Instead I felt the first scratchings of panic. If [the hospital] weren't going to look after me, who was?" [1].

Completing cancer treatment marks a major transition with new challenges for patients and families [2-3]. Systematic reviews have highlighted the importance of follow-up care [4] and preparing patients for the longer-term impact after treatment [5]. Similarly, family caregivers may also need preparation and support to adjust after treatment [6-11]. They can face various associated difficulties including stress, psychological and physical health problems, sleep disturbances and financial impact [12]. However, there is a lack of adequate support offered to caregivers [13-14] and they tend not to seek support for themselves [15-16]. This may contribute to the broad range of unmet needs reported by partners and caregivers of adults with cancer [17].

Fletcher and colleagues' [18] review of cancer family caregiving outlines stress processes affecting family caregivers over the course of the illness. The authors suggest that a developing line of enquiry which may offer important insights into caregiving is caregiver-patient pairs, or 'dyads'. This was echoed by Hagedoorn *et al.*, whose review concluded that further studies are needed "to increase our knowledge of dyadic processes in cancer adaptation" [19]. This is of direct clinical relevance given the impact of dyadic processes on patients' and caregivers' physical and mental health [20-21]. Indeed, the efficacy of psychosocial interventions for cancer caregivers may be influenced by the patient-caregiver relationship, and a systematic review recommended further research on this topic [22].

In patient-partner dyads (couples), most research to date has explored experiences of breast or prostate cancer [23]. The present study focused on couples' adjustment after colorectal cancer. Treatment and recovery from colorectal cancer can require considerable post-treatment care at home, affecting partners as well as patients [24-25]. Qualitative studies have helped to explore different aspects of patients' experiences of colorectal cancer such as the psychosocial impact and quality of life [26-30], adjustment to diagnosis and treatment

[31-35] including an ostomy or stoma [36-37], and healthcare needs or preferences [16, 38-43]. Qualitative research on partners' or relatives' experiences has explored diverse topics including reactions to diagnosis [44], information needs [45], the impact of treatment [46-50], caregiving and daily life [51-52], along with the economic and emotional consequences [53].

The present study sought to build on the existing evidence-base by focusing on two areas where the need for further research has been identified. Firstly, by adopting a multi-perspective qualitative methodology [54], the study aimed to provide a more detailed analysis of patient-caregiver dyads, a gap identified in recent research [18-19, 22, 56-57]. The approach compares accounts *within* as well as *between* couples, providing a richer understanding of complex relationship dynamics and how these affect experience [58]. Secondly, there is a recognised need for studies that include both cancer survivors and their caregivers after completion of treatment [56], which is noted to be a key transition period [59]. The study therefore aimed to explore couples' experiences of colorectal cancer services from the perspectives of both patients and their partners, focusing on the transition to survivorship.

Methods

Design

Qualitative methodology was adopted to facilitate in-depth exploration of individual experiences [60]. Specifically, Framework Analysis [61] provided a systematic approach that maintained transparency through access to original textual data. As an iterative process, it enabled amendment and additions to the analytic framework throughout, grounding the analysis in participants' accounts. The Framework method allowed for dyadic analysis [62-63], aided by separate interviews for patients and their partners [58].

Participants

Participants were purposefully selected for their ability to provide depth and diversity of responses relevant to the study [64] (see Appendix 3). Purposeful sampling involves the intentional selection of participants who are able to provide a 'richness' or depth of information pertaining to the research question. The aim is not to acquire a sample that is statistically representative of a population or achieve generalization [61]. In seeking depth rather than breadth, purposeful sampling enables a focused and detailed level of relevant information to be obtained. In the present study, participants who met the inclusion criteria

were known to the Cancer Nurse Specialist responsible for recruiting to the study, who selected those invited to participate based on their ability to provide detailed and varying perspectives on the study topic. Inclusion criteria were an English-speaking adult patient or partner of a patient who had completed treatment of curative intent within the past 12 months for their first diagnosis of colorectal cancer. Exclusion criteria were a patient or partner of a patient currently undergoing treatment for cancer, or for whom there had been a recurrence of cancer, or where treatment was known to have failed curative intent. During routine follow-up, the Cancer Nurse Specialist ascertained individuals' suitability and interest in participating. Those identified were provided with further information by the first author. Seven individuals declined to participate (stated reasons were: too busy (n=4), unwell (n=1), hard of hearing (n=1), not interested (n=1)). 10 participated after providing written informed consent. Details are provided of the sample, including allocated pseudonyms (Table 2.1).

Data Collection

Separate interviews gave participants the opportunity to talk about their experiences from their perspective without the presence of their partner affecting or interrupting their account. This provided a clearer distinction of the voices of each individual within the couple, whilst preserving the ability to compare between different couples' narratives [58]. Interviews followed a semi-structured schedule (Appendix 4), focusing on experiences of services around completion of treatment, and the impact on their relationship. Participants were debriefed after the interview. Interviews were audio-recorded, transcribed and anonymised by the first author, who also recorded reflections following each interview. Data-driven analysis was conducted concurrently with data collection and informed the point at which data were deemed sufficient and recruitment was completed [65].

Data Analysis

Analysis of interview transcripts and the first author's reflections adhered to the five step process of Framework Analysis [61]. This involved: first, becoming familiar with the data through transcribing, repeatedly reading and reflecting on the data; second, developing an initial thematic framework based on key concepts from participants' accounts, which was used to begin organising and classifying the data; third, identifying and indexing portions of data relating to specific themes, represented as codes; fourth, reorganising data into charts of the themes, using headings to compare across the whole dataset whilst keeping reference to the original context; fifth, searching for patterns and explanations and using diagrams to develop interpretations (Appendices 5a-d). In addition to analysis of individual interviews, dyadic analysis compared overlaps and contrasts within and between couples [58]. This highlighted differences in couples' relational styles as well as individual differences for the sample of patients compared with partners.

Table 2.1 Sample characteristics

Pseudonym	Gender	Age	Ethnic origin	Employment status	Treatment type	Months post-treatment	Marital status	Duration of relationship
Arthur (patient)	M	69	White, British	Retired	Surgery and Chemotherapy	4	Cohabiting	15 years
Agnes (partner)	F	73	White, British	Retired				
Beth (patient)	F	72	White, British	Retired	Surgery and Chemotherapy	3	Married	51 years
Bruce (partner)	M	72	White, British	Retired				
Colin (patient)	M	67	White, British	Retired	Surgery, Radio- & Chemotherapy	2.5	Married	45 years
Claire (partner)	F	67	White, British	Retired				
Dawn (patient)	F	63	White, British	Retired	Surgery and Chemotherapy	2	Married	46 years
David (partner)	M	64	White, British	Employed				
Evan (patient)	M	40	White, British	Self-employed	Surgery and Chemotherapy	2	Cohabiting	5 years
Emma (partner)	F	33	White, British	Employed				

Rigour

The study received ethical approval from institutional research ethics boards (Appendix 8). Strategies were adopted to improve the trustworthiness of the findings, with reference to recommended criteria for ensuring rigour in qualitative research [64, 66]. Details of the researchers, study design, analysis and findings are summarised according to the consolidated criteria for reporting qualitative research (COREQ; see Appendix 3) [64]. A consultation group of four patients and one partner-caregiver provided input on development of the study, including the participant information sheets and consent forms, the interview schedule, and the analytic framework. This was conducted in line with recommendations on service user involvement [67]. Invitation to volunteer for the consultation group was widely distributed to service users and caregivers. Those who expressed interest were not excluded unless they were unable or unwilling to agree to terms of involvement (Appendix 7). This ensured that the first author remained open to a diverse range of perspectives and did not 'cherry-pick' consultants. Five individuals volunteered which helped ensure that a range of feedback was obtained. While all volunteers had personal experience of cancer, they were not eligible for participation in the study and therefore involvement in the consultation group did not detract from recruitment of potential participants. Participants were invited to give feedback or 'member reflections' [68] on a written summary of the findings. In addition, the co-author and consultation group provided alternative viewpoints to the first author's perspective. By addressing overlap and contrast, the dyadic analysis actively sought contradictory views, facilitating negative case analysis.

Results

The three overarching themes identified were: recovery, relationship dynamics, and healthcare services. Within each of these themes, findings are reported under three categories of dyadic analysis: overlap within and between couples, contrast between couples, and contrast within couples.

Recovery: *'pick yourself up and get on as best you can'*

There was overlap within and between couples' narratives of recovery following treatment for colorectal cancer. Recovery was helped or disrupted by the extent to which cancer affected their lives physically, emotionally and more broadly, and by people's responses or

coping styles. One of the most notably recurrent themes, found in every interview, was that of 'stoicism', which was prevalent in both patients' and partners' narratives. The three aspects of stoicism described by Wagstaff and Rowledge [69] were identified in the data. These were: emotional non-involvement, lack of free expression of emotions, and exercise of emotional control to withstand difficulties, with the latter found to be most prevalent.

"Everybody keeps saying, 'Did you have a good cry about it?' and I haven't. Not yet. And I don't think now I ever will." (Dawn)

"I suppose it was an unsaid thing. ...Me, I didn't mention it, just sort of kept it to myself." (David)

"Life's not always plain sailing. And things do go wrong, you know. And you've to pick yourself up and get on as best you can." (Beth)

Related to this third aspect, some participants perceived stoicism as a helpful source of strength or way of coping with adversity, and even attached a sense of identity to it.

"It's just my nature. Just tell me what's up and I'll get on with it" (Dawn)

However, in some instances, such as the lack of free expression of emotions, it resulted in unshared feelings and concerns, or formed a barrier to accessing support. The following quotation illustrates both of these consequences.

"There've been days she [the patient] was pretty unhappy about her situation... Maybe she should have phoned the nurse more than she did to see what was available but again, I suppose, we are folk that dinna [don't] ask for help... what she feels-, or, well, felt, deep inside, I'll probably never know. Em, she probably kept some of that to herself all the way through this. Put a brave face on it... She didn't know what was available or what else was on the go. And being her, she wouldn't ask either." (David)

The analysis also highlighted areas of contrast between couples. Some reported a relatively straight-forward recovery journey, whereas others encountered various complications which impeded their progress. Several of the couples described side-effects having a lasting impact on the patient's mood and irritability after completion of treatment. This was contrasted by another couple, Arthur and Agnes, who both viewed recovery as 'plain sailing'.

"I do snap at him sometimes - I still lose my temper sometimes." (Beth)

"She started to get a bit of a temper. You know, it was

frustration more than anything else.” (Bruce)

“I dinnae [don’t] think I felt frustrated, like. I dinnae think I felt that since day one.” (Arthur)

“He’s a placid kind of laddie, he doesnae- [doesn’t] , he never gets bad tempered or nothing” (Agnes)

Irritability, frustration and low mood were compounded if the patient’s expectations of a timely recovery were not met, as illustrated by Colin’s description of his experience after treatment. Similarly, his partner spoke of the initial post-treatment period as a challenging time, navigating the tension between trying to help while needing to allow the patient space to recover.

"I just thought, 'It was an operation, give me a couple of weeks and I'll be up and about'. But that was nae [not] the case... [Recovery] was very, very slow. In fact I thought it wasnae [wasn't] even moving. I was just sort of stuck... I realise that now, that I was actually getting better but it was so slow that I couldnae [couldn't] see it within myself." (Colin)

"He struggled quite a bit. And he just wanted to be sort of on his own often, just shut away, and: 'Dinna bother wi' [with] me... Just shut the bedroom door, I want to sleep...' So, it was quite hard going that time. Because, maybe we're over-protective, I dinna know, but, eh, ken [you know], you're aye [always] wanting to help. But sometimes you have to step back a wee bit and let them get through things themselves" (Claire)

The broader impact on their lives also varied. For some couples, there were considerable and lasting consequences for their work, social or home life, whereas others emphasised how little disruption they had faced. The wider life context appeared to be an important factor, with a more complicated recovery for those facing concurrent stressors such as financial concerns or other health problems.

Contrast within couples was also evident when comparing the narratives of patients with their partners. For instance, Beth said she was now “*quite optimistic*” about the future, whereas her husband described feeling “*just, apprehensive... that something could go wrong now.*” Patients and partners were not necessarily aware of what each other found most difficult. For example, Evan said that he had found the on-going financial worry was the most challenging part and said that he thought this was also the case for his partner, Emma. However, she said the hardest part was the initial period of “*not knowing and waiting*” which was now past and assumed this was also true for Evan.

Relationship dynamics: 'what I'm going through, she goes through as well'

In every interview, there was a theme of cancer as a shared experience, which couples said 'we' faced and survived together, even in relation to the patient's physical symptoms or medical care.

"We had a lot of accidents wi' my stoma" (Colin)

"Hopefully we'll get this reversal and get nearer back to normal." (Claire)

"What I'm going through, she goes through as well, em, 'cause we're basically a team." (Evan)

"I think we were quite lucky in the way it happened... we got through it" (Emma)

The above quotations illustrate that partners closely identified with the patient's experience and, similarly, that patients thought of cancer as something they were facing together. Despite the challenges for their relationship, several participants said that cancer ultimately had little or no impact on their relationship, or even a positive impact.

"[The experience with cancer] kind of made it a bit softer in our relationship... if we have an argument or something, I'll think of that week [going for chemotherapy], and it reminds me of the-, how important he is to me and to my family. So, we've spoke about getting married ...when you argue wi' somebody and fall out and that, it's so easy to walk away. But when you've been through something like this, it makes you realise just how important that person- it's made a big difference, for me, for our relationship." (Emma)

However, the perception of being involved in the cancer experience could be complicated for partners by a concurrent sense of being helpless and restricted to being an onlooker, a tension which David illustrated.

"...obviously I was caught up in it. But I was, like, a, just a bystander. I couldn't help in any practical way." (David)

Some of the patients acknowledged their partner's sense of helplessness but described how their partner was actually a "rock" for them, a vital source of support and stability. As Colin expressed, *"I doubt I maybe could have survived if I'd just been on my own."* In turn, partners emphasised how mutual support had helped them to cope. The importance of patient-partner reciprocal influence was highlighted, as described by one partner with a touch of humour.

"...being strong helped him [the patient] be strong... I think if he'd spiralled

downwards, em, there would have been more of a fight for me to get him back up. And that kind of kept me strong, 'cause he stayed up the whole time... I don't think anybody could have supported us as well as what we did for each other. And see if he doesn't say the same thing, I'll kill him myself. [laughs]"
(Emma)

An area of contrast between couples was communication and the extent to which thoughts and feelings were shared or hidden. For one couple, it was the partner who prompted the patient to seek medical advice.

"I thought it was his prostate 'cause he'd to-, that's why we sort of pushed for getting appointments at the hospital, ken, with the doctors, like, ken. I used to keep saying, 'Did you ask about it? Did you ask about it?'" (Agnes)

However, another partner said she initially chose not to share her concerns about the possibility of a cancer diagnosis with the patient to spare him concern.

"It was in my mind that he had cancer. But he didn't think that at all...I did think, but I kept it to myself, but fae [from] the very start I said it was cancer. But, I'm quite happy that he didnae [didn't] realise right at the minute that it was cancer." (Claire)

Some things were not openly discussed simply because the person assumed they knew what the other thought or wanted. In other instances, participants said that they deliberately left things unspoken in an attempt to avoid upsetting the other. Both patients and partners alike described trying to protect each other in this way.

"I probably didn't say as much as I should have, just to sort of protect him a little bit." (Beth)

"I would try to be careful nae [not] to saying anything that would upset her too much." (David)

Differing relational styles were also apparent. For some couples, preserving a degree of mutual independence was important to the successful functioning of their relationship. Others preferred a more mutually-dependent lifestyle.

"You've your own interests and your own friends, you know. Whereas if you're just a couple, and you don't do anything apart from each other, you're lost."
(Beth)

"We're quite happy 'cause we do everything together and, eh, no, things work. Because if I go out walking, she comes wi' me, and if we're going anywhere at weekends or anywhere we go – we never go on holiday separately, we always go together." (Colin)

Within couples, there were some contrasting perceptions of each other's experiences. Some patients and partners said they thought it was more difficult for the other person.

"I think my husband was actually more bothered by it than I was" (Dawn)

"Once you've gone through that, it's got to leave an impression. Not so much for me but more for Dawn." (David)

Contrasting opinions also emerged within couples. For instance, Emma said that she wanted to tell the children about the diagnosis from the outset but that Evan did not want to initially.

Healthcare Services: 'leaving you to get on with it'

There was little overlap between couples in terms of their reported experiences and opinions of healthcare services. Participants shared the view that adequate information and availability of healthcare professionals were important, but differed on whether or not they had received these themselves. When asked, the reply from every participant was that there had not been any offer or suggestion of support specifically for the partner. While all the partners in the sample accompanied the patient to hospital, not all were made aware that they could attend appointments jointly.

"I wasnae really involved – I didnae realise that you could go through. I thought it was just for him." (Claire)

There was notable contrast between different couples' reported experiences of healthcare services, but within each of the couples interviewed, there was a high degree of overlap in the opinions of healthcare shared between patients and their partners. Where the patient perceived good availability of support, this was echoed in the narrative of their partner.

"If there was anything outwith, I've got numbers to just give them a ring. Ken. So I've found it excellent. ...the back-up and everything was there." (Colin)

"We've had brilliant- all the way through...We could have phoned any of them at any time, uh huh, which was good." (Claire)

Similarly, where the patient expressed dissatisfaction or disappointment with an aspect of their healthcare, this too was evident in their partner's account.

"Quite a lot of them are not very good at telling you what, what's going on." (Dawn)

"They're not giving you a lot of information." (David)

Participants' specific suggestions for service improvements across the cancer trajectory were summarised (Table 2.3). These illustrated how even simple measures could be perceived as a valuable source of practical, emotional and informational support.

Different couples held differing preferences for follow-up care. Beth and Bruce commented on their relief that she was not required to go for a more frequent scan, since they both perceived this as indication of a better prognosis. Conversely, Agnes and Arthur indicated that they would have preferred to have a scan sooner and that waiting for results was an anxious and difficult time. Emma also said that her preference would have been for Evan to receive more regular scans and attributed the delay to services trying to save money.

Some participants spoke with high regard for the healthcare they had received. They commended the pleasant and personable staff who took time to explain or discuss issues and showed personal interest by talking more informally, remaining available to answer questions when necessary. By contrast, some participants reported negative experiences of healthcare, such as not being kept informed but left waiting for treatment or results. Some felt that staff lacked the time or resources to provide support, or that it was unclear what support was available, if any.

"I know that in here, a week in here is just- it, it doesn't mean nothing because it's just, they're so busy, so busy and things like that, but it-. But a week to me would seem to be a lifetime really because I was thinking, 'What's happening? What's happening?'" (Colin)

The perception of being seen as "just a number," as well as a lack of further information or follow-up, contributed to feeling "left" or "deserted" after treatment completion, as described by some patients and one partner.

"[There was] nothing helpful in the sense, eh, well as far as I know, eh, sort of like, 'Have you seen about this, have you seen about that, did you know that this was available?' that kind of thing. I don't know of anything like that. I thought it was, em, how to say? Kind of leaving you to get on with it." (David)

Table 2.2 Participants' suggestions for healthcare services**Summary of suggested service improvement****Following diagnosis**

Ensure an experienced healthcare professional is available to answer questions in the hours or early days after receiving a diagnosis.

Provide proactive and personalised information and support from the outset by asking and offering, rather than waiting for patients or relatives to ask for help.

Ask partners or relatives, as well as patients, whether they have any questions and check that they have the information they need.

Offer a separate appointment for partners to check what their understanding is and how they are coping.

During treatment

Offer some lunch or a cup of tea or coffee for partners who are waiting with patients during a full day of treatment.

Provide a service where there are staff or volunteers who can offer to sit and talk with patients who are admitted to hospital but do not have visitors or family support locally.

After treatment

Supply thin cotton gloves for people affected by treatment side-effects of 'pins and needles' so that they can handle things (e.g. cold items from the fridge) with less discomfort.

Prepare people for the possibility that recovery can take weeks or months after finishing treatment.

Ensure that people are directed towards relevant sources of information and support, so that they are more aware of what help is available to them.

Offer contact with a former service user, someone who has successfully recovered, to help share and 'normalise' experiences.

Offer more frequent follow-up scans.

Provide an informal follow-up telephone call to enquire about progress and recovery a few months after the completion of treatment.

Despite the high concordance between patients' and their partners' perceptions of healthcare services, some contrasting views were evident within couples. Beth and Bruce described services as a highly efficient system. However, for Beth, this actually contributed to the feeling of anonymity and abandonment.

"You're booked in and it's just a seamless operation... you sort of find you're in the system and you're just a number ...you're just passing through the system, you know. It's just so organised ... you've all this attention and then suddenly it all disappears. You know, you're left to get on with it. ...you feel a bit let down I think. You think, 'Okay, they've done all this, but they don't really want to know any more about you' ... I feel deserted, really." (Beth)

By contrast, her husband perceived the efficiency as wholly positive.

"...when we come back, 'We've made an appointment for you at the hospital.' Just done like that. Found they were very efficient that way. ...I couldn't fault them." (Bruce)

There were also differences in how patients and partners obtained and understood information. For instance, Dawn described having received test results by telephone prior to her follow-up appointment but it would appear that this information was not shared with her partner, who described the tension he felt waiting to be called in to that appointment to get the results. Similarly, it appeared that Colin knew the planned ending for contact with a community nurse, whereas his wife did not know this. Even where information was given to both, it could be understood differently by the patient and partner, as Evan illustrated when describing the appointment to get results after treatment:

"Never exactly said that you were clear. Eh, you know, Emma's: 'You got the all clear,' but she [the doctor] never exactly said that." (Evan)

Discussion

Clinical Implications

There is growing recognition of the broad and long-term impact of cancer on patients and partners who can encounter different difficulties across the cancer trajectory [2-3], as found in the present study. While the importance of screening for on-going distress in patients has been emphasised [70], assessing the needs of partners and caregivers is less widely-practised [71], even though some experience greater distress than patients [72]. Patients' and partners' description of cancer as a shared experience [73] supports a systemic approach to healthcare [74]. Services can draw upon a patient's support network as a significant resource, while remaining mindful of the impact of relationship dynamics and potential difficulties for patients and families [75].

By comparing overlap and contrast within and between couples, the findings highlight the importance of person-centred care to accommodate different preferences for information, family involvement or frequency of follow-up, for example [76-77]. Although some couples feel well-supported by healthcare services throughout their journey, others feel let down and

deserted after treatment [43]. This reflects a number of factors including: disparity of access to services, differences in uptake of what is available, as well as differences in specific needs, expectations and attitudes to help-seeking [78-79]. The perceived availability of support can be important in itself. Even when couples do not need or choose to contact staff after completing treatment, they may be reassured by knowing who to contact if necessary. Some of the study participants' most valued follow-up was timely telephone contact lasting a few minutes at most. All that may be required is a brief word of reassurance, normalising their experiences, or directing towards relevant resources.

The findings reaffirm the importance of communication in healthcare [80], a recurrent theme in participants' reported experience of services. For instance, clearly explaining the rationale for the length of time between scans could alleviate concerns and improve satisfaction with services. Healthcare professionals should be aware that information given to the patient is not necessarily shared with their partner or caregiver. Where appropriate, staff should keep caregivers informed and check whether they also have questions about healthcare and follow-up plans. Evidently, there is value in taking time to ensure patients and their relatives understand the information they have been given, have had their questions addressed, and feel recognised as individuals. However, this sits in tension with participants' descriptions of healthcare teams as highly busy and under-staffed. The difficulty of stretched resources highlights the need for prioritising resource allocation to protect staff time and provide relevant training.

Underlying a stoical presentation, people can be facing significant difficulties where additional information or input could reduce worry or distress. Therefore, a proactive approach by healthcare services may be necessary [16], with sensitivity to individual and cultural differences. Where there are unshared concerns, a balance is needed to promote recovery and access of relevant support without undermining a stoical coping style or self-identity. While findings of age and gender differences in stoicism [69, 81-82] were not observed in this sample, cultural factors may have predominated. Stoicism can be a particular feature of certain cultures such as the British 'stiff upper lip' [69] or ethnic minorities [83]. For example, there is some evidence that stoical attitudes are more prevalent in rural contexts [84-86]. This may help to explain the prevalence of the theme in the present study, given that the participants were from British, rural communities.

Even where couples show considerable resilience in their relationships [87], as in the current

study, there are evidently challenges and strain placed on relationships over the course of the illness. This can draw couples together but it can also lead to unshared concerns and other difficulties. Dyadic analysis highlighted the potential for miscommunication and misunderstandings within couples. Mood changes continuing after treatment, such as increased irritability, appear to be common for patients and can put additional pressure on their relationships. It may be helpful to enquire about how the patient is coping emotionally with treatment side-effects to assess whether there is a high level of frustration and consider the impact on the partner and relationship. In addition, some individuals place a high value on independence within their relationship. Healthcare professionals should be alert to potential difficulties where physical impairment and reduced functioning necessitate greater dependence for the patient. This can prevent patients and partners from having adequate time and space to themselves which can be particularly problematic for some couples, depending on their usual or preferred style of relationship. Awareness and assessment of this by the healthcare team can identify those who may benefit from additional support such as respite care [88].

Limitations

The methodology sacrificed 'breadth' for 'depth', limiting generalisability of results. To improve homogeneity, the sample did not include other relationships such as parent-child patient-caregiver dyads, or other cancer types, stages and outcomes. Furthermore, couples were only included where both consented to participate. The sample was therefore biased towards relatively cohesive couples. It is less likely that both patient and partner would participate where there were relationship difficulties or separation, and yet these may be the couples for whom the issues raised in the study are most pertinent. Involving a member of the patient's healthcare team in recruitment could also have biased the sample. Those lost to follow-up, or known to have negative views of healthcare, may have been less likely to be invited or willing to participate.

At points where participants described or displayed feeling upset, the first author reflected on the difficulty of not taking on a dual role of clinician as well as interviewer. Consequently, some topics were not pursued more deeply, which may have missed relevant information.

The first author's perspective, prior expectations and knowledge influenced the process through the choice of specific interview questions and through decisions made during analysis and reporting of results. It is inevitable and appropriate that the topics which

participants are asked about shape the direction and content of the interviews and thus influence the themes which are raised. However, care is necessary to ensure analysis remains open to participants' perspectives and does not restrict analysis by imposing preconceived ideas onto the data. Reflexivity and transparency are critical in making best use of the active role the researcher plays in interpretation and reporting of results [60]. The value of moving from anecdotal to empirical evidence should not be negated, but the design should also remain open to unexpected or contradictory findings.

In the present study, efforts were made to ensure the use of relatively broad, open-ended questions, with prompts for further information and clarification as necessary throughout the interviews, to allow space for the unexpected to arise. However, it is acknowledged that the first author's perspective influenced the development of both the interview schedule and the analytic framework. It is noted that the three identified themes closely correspond to the topics of the interview schedule. This may suggest the influence of prior conceptualisation on how the first author made sense of the data, labelled or defined themes and presented results. Efforts to relate the findings to the study aims affected how results were reported. Although member reflections were sought by inviting feedback on a summary of findings sent by post to each of the participants, unfortunately none of the participants had responded to this invitation at the time of reporting. However, alternative perspectives to that of the first author were also sought from the co-analyst and consultation group. With sufficient resources, future research could adopt a broader or extended interview schedule, purposefully sample a larger or more diverse sample, include second interviews with participants separately or jointly as a couple, and adopt other methods for obtaining member reflections. Such measures could help address the limitations of the data collection, analysis and reporting acknowledged in the current study.

Future Research

Further comparison with other types of caregivers, and with other types and stages of cancer, would help distinguish issues specific to the study population from issues which apply more broadly. Broadening recruitment to purposefully select couples with relationship difficulties could enable fuller analysis of interpersonal dynamics. It would also be informative to explore dynamics between couples and the healthcare team more fully by including relevant healthcare professionals within multi-perspective analysis [54, 89]. Ways of facilitating good communication within couples and with the healthcare team could be fruitful avenues for future research [90]. Further exploration of the cultural influences on coping styles such as

stoicism, and its influence on communication and on help-seeking behaviour, may shed light on barriers to accessing services [78, 83].

Conclusions

The physical, emotional and broader impact of cancer can endure beyond the completion of treatment, particularly for those who encounter medical complications or other concurrent difficulties. Survivors and partners can have a significant impact on each other through their experiences and responses during this recovery process. Their awareness of this reciprocal influence may contribute to efforts to appear stoical, partly to avoid causing each other concern, which can result in unshared difficulties or concerns. Healthcare professionals have a role in facilitating good communication and ensuring adequate support is made available to couples and families as a whole.

References

1. Diamond J. C: *Because Cowards Get Cancer Too*. London: Vermilion; 1998. p.225.
2. Blum K, Sherman D. Understanding the experience of caregivers: A focus on transitions. *Semin Oncol Nurse* 2010; 26:243-258.
3. Mitschke D B. Cancer in the family: Review of the psychosocial perspectives of patients and family members. *J Fam Soc Work* 2008; 11:166-184.
4. Lewis R A, Neal R D, Hendry M, France B, Williams N H, Russell D et al. Patients' and healthcare professionals' views of cancer follow-up: Systematic review. *Br J Gen Pract* 2009; 59:e248.
5. Bennion A, Molassiotis A. Qualitative research into the symptom experiences of adult cancer patients after treatments: A systematic review and meta-synthesis. *Support Care Cancer* 2012; 21: 9-25.
6. Bevans M, Stenberg E. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA* 2012; 307:398-403.
7. Girgis A, Lambert S D, Mcelduff P, Bonevski B, Lecathelinais C, Boyes A et al. Some things change, some things stay the same: A longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psychooncology* 2013; 22:1557-1564.
8. Given B, Sherwood P, Given C. Support for caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiol Biomarkers Prev* 2011; 20:2015-2021.
9. Given B A, Given C W, Sherwood P R. Family and caregiver needs over the course of the cancer trajectory. *J Support Oncol* 2012; 10:57-64.
10. Li Q, Mak Y, Loke A. Spouses' experience of caregiving for cancer patients: A literature review. *Int Nurs Rev* 2012; 60:178-187.
11. Stenberg U, Ruland C, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology* 2010; 19:1013-1025.
12. Northouse L, Williams A, Given B, Mccorkle R. Psychosocial care for family caregivers of patients with cancer. *J Clin Oncol* 2012; 30:1227-1234.
13. Adams E, Boulton M, Rose P, Lund S, Richardson A, Wilson S et al. A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care. *Support Care Cancer* 2012; 20:2785-2794.
14. Sinfield P, Baker R, Ali S, Richardson A. The needs of carers of men with prostate cancer and barriers and enablers to meeting them: A qualitative study in england. *Eur J Cancer Care* 2012; 21:527-534.
15. Bevans M, Wehrle L, Prachenko O, Soeken K, Zabora J, Wallen G. Distress screening in allogeneic hematopoietic stem cell (HSCT) caregivers and patients. *Psychooncology* 2011; 20:615-622.
16. Hall S, Gray N, Browne S, Ziebland S, Campbell N. A qualitative exploration of the role of primary care in supporting colorectal cancer patients. *Support Care Cancer* 2012; 20:3071-3078.
17. Lambert S D, Harrison J D, Smith E, Bonevski B, Carey M, Laws C et al. The unmet needs of partners and caregivers of adults diagnosed with cancer: A systematic review. *BMJ Support Palliat Care* 2012; 2:224-230.
18. Fletcher B, Miaskowski C, Given B, Schumacher K. The cancer family caregiving experience: An updated and expanded conceptual model. *Eur J Oncol Nurs* 2012; 16:387-398.
19. Hagedoorn M, Kreicbergs U, Appel C. Coping with cancer: The perspective of patients' relatives. *Acta Oncol* 2011; 50:205-211.
20. Meyler D, Stimpson J P, Peek M K. Health concordance within couples: A systematic review. *Soc Sci Med* 2007; 64:2297-2310.

21. Walker R B, Luszcz M A. The health and relationship dynamics of late-life couples: A systematic review of the literature. *Ageing Soc* 2009; 29:455-480.
22. Waldron E, Janke E, Bechtel C, Ramirez M, Cohen A. A systematic review of psychosocial interventions to improve cancer caregiver quality of life. *Psychooncology* 2012; 22:1200-1207.
23. Hopkinson J, Brown J, Okamoto I, Addington-Hall J M. The effectiveness of patient-family carer (couple) intervention for the management of symptoms and other health-related problems in people affected by cancer: A systematic literature search and narrative review. *J Pain Symptom Manage* 2012; 43:111-142.
24. Denlinger C S, Barsevick A M. The challenges of colorectal cancer survivorship. *J Natl Compr Canc Netw* 2009; 7:883-894.
25. Jansen L, Koch L, Brenner H, Arndt V. Quality of life among long-term (≥ 5 years) colorectal cancer survivors—systematic review. *Eur J Cancer* 2010; 46:2879-2888.
26. Dunn J, Lynch B, Rinaldis M, Pakenham K, Mcpherson L, Owen N et al. Dimensions of quality of life and psychosocial variables most salient to colorectal cancer patients. *Psychooncology* 2005; 15:20-30.
27. Ness R M, Holmes A, Klein R, Greene J, Dittus R. Outcome states of colorectal cancer: Identification and description using patient focus groups. *Am J Gastroenterol* 1998; 93:1491-1497.
28. Persson E, Hellström A L. Experiences of Swedish men and women 6 to 12 weeks after ostomy surgery. *J Wound Ostomy Continence Nurs* 2002; 29:103-108.
29. Ramfelt E, Severinsson E, Lützén K. Attempting to find meaning in illness to achieve emotional coherence: The experiences of patients with colorectal cancer. *Cancer Nurs* 2002; 25:141-149.
30. Sahay T B, Gray R E, Fitch M. A qualitative study of patient perspectives on colorectal cancer. *Cancer Pract* 2001; 8:38-44.
31. Hou W K, Lam W W T, Fielding R. Adaptation process and psychosocial resources of Chinese colorectal cancer patients undergoing adjuvant treatment: A qualitative analysis. *Psychooncology* 2009; 18:936-944.
32. Houldin A D, Lewis F M. Salvaging their normal lives: A qualitative study of patients with recently diagnosed advanced colorectal cancer. *Oncol Nurs Forum* 2006; 33:719-725.
33. Hubbard G, Kidd L, Kearney N. Disrupted lives and threats to identity: The experiences of people with colorectal cancer within the first year following diagnosis. *Health* 2010; 14:131-146.
34. Taylor C. Patients' experiences of 'feeling on their own' following a diagnosis of colorectal cancer: A phenomenological approach. *Int J Nurs Stud* 2001; 38:651-661.
35. Taylor C, Richardson A, Cowley S. Restoring embodied control following surgical treatment for colorectal cancer: A longitudinal qualitative study. *Int J Nurs Stud* 2010; 47:946-956.
36. Grant M, McMullen C K, Altschuler A, Mohler M J, Hornbrook M C, Herrinton L J et al. Gender differences in quality of life among long-term colorectal cancer survivors with ostomies. *Oncol Nurs Forum* 2011; 38:587-596.
37. McMullen C K, Hornbrook M C, Grant M, Baldwin C M, Wendel C, Mohler M J et al. The greatest challenges reported by long-term colorectal cancer survivors with stomas. *J Support Oncol* 2008; 6:175-182.
38. Bain N S C, Campbell N C, Ritchie L D, Cassidy J. Striking the right balance in colorectal cancer care—a qualitative study of rural and urban patients. *Fam Pract* 2002; 19:369-374.
39. Beaver K, Latif S, Williamson S, Procter D, Sheridan J, Heath J et al. An exploratory study of the follow-up care needs of patients treated for colorectal cancer. *J Clin Nurs* 2010; 19:3291-3300.

40. Mccaughan E, Parahoo K, Prue G. Comparing cancer experiences among people with colorectal cancer: A qualitative study. *J Adv Nurs* 2011; 67:2686-2695.
41. Mccaughan E, Prue G, Parahoo K, Mcilpatrick S, McKenna H. Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer after chemotherapy treatment: A qualitative longitudinal study. *Psychooncology* 2012; 21:64-71.
42. Rozmovits L, Rose P, Ziebland S. In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer. *J Health Serv Res Policy* 2004; 9:159-164.
43. Simpson M, Whyte F. Patients' experiences of completing treatment for colorectal cancer in a Scottish district general hospital. *Eur J Cancer Care* 2006; 15:172-182.
44. Northouse L L, Schafer J A, Tipton J, Metivier L. The concerns of patients and spouses after the diagnosis of colon cancer: A qualitative analysis. *J Wound Ostomy Continence Nurs* 1999; 26:8-17.
45. Broughton M, Bailey J, Linney J. How can experiences of patients and carers influence the clinical care of large bowel cancer? *Eur J Cancer Care* 2004; 13:318-327.
46. Emslie C, Browne S, Macleod U, Rozmovits L, Mitchell E, Ziebland S. 'Getting through' not 'going under': A qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Soc Sci Med* 2009; 68:1169-1175.
47. Norlyk A, Martinsen B. The extended arm of health professionals? Relatives' experiences of patient's recovery in a fast-track programme. *J Adv Nurs* 2012; 69:1737-1746.
48. Persson E, Severinsson E, Hellström A L. Spouses' perceptions of and reactions to living with a partner who has undergone surgery for rectal cancer resulting in a stoma. *Cancer Nurs* 2004; 27:85-90.
49. Ohlsson-Nevo E, Andershed B, Nilsson U, Anderzén-Carlsson A. Life is back to normal and yet not—partners' and patient's experiences of life of the first year after colorectal cancer surgery. *J Clin Nurs* 2011; 21:555-563.
50. Ohlsson-Nevo E, Andershed B, Nilsson U, Anderzen-Carlsson A. Finding a wider horizon: Experiences of being a next-of-kin of a person suffering from colorectal cancer as told after having participated in a psychoeducational program. *Eur J Oncol Nurs* 2012; 17:324–330.
51. Houldin A D. A qualitative study of caregivers' experiences with newly diagnosed advanced colorectal cancer. *Oncol Nurs Forum* 2007; 34:323-330.
52. Sjoval K, Gunnars B, Olsson H, Thome B. Experiences of living with advanced colorectal cancer from two perspectives - inside and outside. *Eur J Oncol Nurs* 2011; 15:390-397.
53. Céilleachair A, Costello L, Finn C, Timmons A, Fitzpatrick P, Kapur K et al. Inter-relationships between the economic and emotional consequences of colorectal cancer for patients and their families: A qualitative study. *BMC Gastroenterol* 2012; 12:62-72.
54. Kendall M, Murray S A, Carduff E, Worth A, Harris F, Lloyd A et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ* 2009; 340:196-199.
55. Beattie S, Lebel S. The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: A comprehensive literature review. *Psychooncology* 2011; 20: 1137-50
56. Mellon S, Northouse L L, Weiss L K. A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nurs* 2006; 29:120-131.
57. Mellon S, Kershaw T, Northouse L, Freeman-Gibb L. A family-based model to predict fear of recurrence for cancer survivors and their caregivers. *Psychooncology* 2007; 16:214-223.
58. Eisikovits Z, Koren C. Approaches to and outcomes of dyadic interview analysis. *Qual Health Res* 2010; 20:1642-1655.

59. Murray S A, Kendall M, Boyd K, Grant L, Highet G, Sheikh A. Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: Secondary analysis of serial qualitative interviews. *BMJ* 2010; 340:c2581-c2581.
60. Smith J. *Qualitative psychology: A practical guide to research methods*. 2nd ed. London: Sage Publications; 2008.
61. Ritchie J, Lewis J. *Qualitative research practice: A guide for social science students and researchers*. 1st ed. London: Sage Publications; 2003.
62. Akeson N, Worth A, Sheikh A. The psychosocial impact of anaphylaxis on young people and their parents. *Clin Exp Allergy* 2007; 37:1213-1220.
63. Singh S P, Paul M, Ford T, Kramer T, Weaver T, McLaren S et al. Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *Br J Psychiatry* 2010; 197:305-312.
64. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19:349-357.
65. O'Reilly M, Parker N. 'Unsatisfactory saturation': A critical exploration of the notion of saturated sample sizes in qualitative research. *Qual Res* 2013; 13:190-197.
66. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3:77-101.
67. Trivedi P, Wykes T. From passive subjects to equal partners: Qualitative review of user involvement in research. *Br J Psychiatry* 2002; 181:468-472.
68. Tracy S J. Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qual Inq* 2010; 16:837-851.
69. Wagstaff G F, Rowledge A M. Stoicism: Its relation to gender, attitudes toward poverty, and reactions to emotive material. *J Soc Psychol* 1995; 135:181-184.
70. Bidstrup P, Johansen C, Mitchell A. Screening for cancer-related distress: Summary of evidence from tools to programmes. *Acta Oncol* 2011; 50:194-204.
71. Mitchell G, Girgis A, Jiwa M, Sibbritt D, Burridge L. A gp caregiver needs toolkit versus usual care in the management of the needs of caregivers of patients with advanced cancer: A randomized controlled trial. *Trials* 2010; 11:115.
72. Couper J, Bloch S, Love A, Macvean M, Duchesne G M, Kissane D. Psychosocial adjustment of female partners of men with prostate cancer: A review of the literature. *Psychooncology* 2006; 15:937-953.
73. Street A, Couper J, Love A, Bloch S, Kissane D, Street B. Psychosocial adaptation in female partners of men with prostate cancer. *Eur J Cancer Care (Engl)* 2010; 19:234-242.
74. Rolland J S. Parental illness and disability: A family systems framework. *J Fam Ther* 1999; 21:242-266.
75. Altschuler J. *Working with chronic illness: A family approach*. 1st ed. Basingstoke: Palgrave Macmillan; 1997.
76. Department of Health. *Improving outcomes: A strategy for cancer - second annual report*. London: Department of Health; 2012.
77. The Scottish Government. *The healthcare quality strategy for NHS Scotland*. Edinburgh: The Scottish Government; 2010.
78. Steginga S, Campbell A, Ferguson M, Beeden A, Walls M, Cairns W et al. Socio-Demographic, psychosocial and attitudinal predictors of help seeking after cancer diagnosis. *Psychooncology* 2008; 17:997-1005.
79. Szczepura A, Price C, Gumber A. Breast and bowel cancer screening uptake patterns over 15 years for UK South Asian ethnic minority populations, corrected for differences in socio-demographic characteristics. *BMC Public Health* 2008; 8:346-361.
80. Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. *Eur J Cancer* 1999; 35:1592-1597.

81. Murray G, Judd F, Jackson H, Fraser C, Komiti A, Pattison P et al. Big boys don't cry: An investigation of stoicism and its mental health outcomes. *Pers Individ Dif* 2008; 44:1369-1381.
82. Yong H, Gibson S, Horne D. Development of a pain attitudes questionnaire to assess stoicism and cautiousness for possible age differences. *J Gerontol B Psychol Sci Soc Sci* 2001; 56:279-284.
83. Anderson K, Richman S, Hurley J, Palos G, Valero V, Mendoza T et al. Cancer pain management among underserved minority outpatients. *Cancer* 2002; 94:2295-2304.
84. Butow P N, Phillips F, Schweder J, White K, Underhill C, Goldstein D. Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: A systematic review. *Support Care Cancer* 2012; 20:1-22.
85. Judd F, Jackson H, Komiti A, Murray G, Fraser C, Grieve A et al. Help-Seeking by rural residents for mental health problems: The importance of agrarian values. *Aust N Z J Psychiatry* 2006; 40:769-776.
86. Moore A, Grime J, Campbell P, Richardson J. Troubling stoicism: Sociocultural influences and applications to health and illness behaviour. *Health* 2013; 17:159-173.
87. Walsh F. Family resilience: A framework for clinical practice. *Family Process* 2003; 42:1-18.
88. Harding R, Higginson I. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 2003; 17:63-74.
89. Yosha A, Carroll J, Hendren S, Salamone C, Sanders M, Fiscella K et al. Patient navigation from the paired perspectives of cancer patients and navigators: A qualitative analysis. *Patient Educ Couns* 2011; 82:396-401.
90. Moore P, Wilkinson S, Rivera Mercado S. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database of Syst Rev* 2009; 1:1-21.

Extended Discussion

The following chapter elaborates on the journal article discussion, providing further comparison of the primary research study with the extant literature.

Recovery: ‘pick yourself up and get on as best you can’

The study lends support to the conceptualisation of cancer treatment completion as a major transition (Murray *et al.*, 2010) that can precipitate certain challenges and uncertainties for both patients and partners (Blum & Sherman, 2010; Mitschke, 2008), providing further evidence of the range of difficulties that can persist over the longer term (Bevans & Stenberg, 2012; Lambert *et al.*, 2012; Northouse *et al.*, 1999). Despite this, the study illustrates how patients and partners do not necessarily access relevant support (Adams *et al.*, 2012; Sinfield *et al.*, 2012; Bevans *et al.*, 2011; Harrison *et al.*, 2012). In some instances, this was due to being unaware of the potential support available, which underscores the importance of providing sign-posting and addressing informational needs (Given *et al.*, 2012). In other cases, accessing support was affected by a stoical coping style.

Stoicism was described by participants as a natural or necessary response to challenging circumstances. At times, stoicism was perceived positively, though it was also acknowledged that stoicism could function to inhibit expression of feelings (Wagstaff & Rowledge, 1995) and prevent help-seeking behaviour. By contrast, Knott and colleagues (2012) reported that patients reverted to showing a ‘brave face’ only after failed attempts to elicit help from others. This raises the question of whether stoicism may be either the cause or result of failure to access support. The study findings affirm Knott and colleagues’ suggestion of educating social and healthcare support networks about the risk of inadvertently increasing patient burden or distress through an excessive emphasis on positivity, or expectations of maintaining a ‘fighting spirit’. However, the current study also indicates that this education could usefully be extended to include patients themselves, who may have internalised similar expectations or beliefs.

Coping styles and accessing support have also been found to be influenced by attachment style, with evidence that securely attached individuals are more likely to seek and use social support (Schmidt *et al.*, 2012). Secure attachment was also associated with an active coping style and positive reframing (Schmidt *et al.*, 2012). The present study did not include

assessment of participants' attachment styles. Given the potential impact on coping and help-seeking as well as relationship dynamics, it remains an avenue warranting further investigation.

In their seminal work on stress and coping, Lazarus and Folkman (1984) presented a transactional model of stress, where perceived demands outweigh perceived resources. According to the model, it is an individual's appraisal of the demands and resources that plays a pivotal role in their experience of stress and coping. The model has been related to family adjustment and adaptation after a child's cancer (Patterson *et al.*, 2004) and has also been applied to cancer in adults. For instance, increased distress in the later stages of the cancer experience, including post-treatment, may be understood as stress resulting from appraising cumulative loss of valued resources (Knott *et al.*, 2012).

The current study illustrated how cancer as a 'stressor', even with a similar prognosis and successful treatment outcome, could be appraised differently by different people. For example, the first couple's account of an unproblematic progression through treatment and recovery contrasts with the times of stress and distress described by others facing an objectively similar illness course. However, the study found that the complexity of participants' experiences did not neatly fit the classic, transactional stress process model. The findings demonstrated how certain factors could be appraised as both a 'demand' and a 'resource'. For instance, cancer treatment itself constitutes an essential resource for recovering from the disease but was also described as a major demand and stressor. Similarly, a stoical attitude could be portrayed as a resource for coping but also place demand on individuals and prevent access of other resources such as healthcare or social support. Evan and Emma's interviews illustrated how returning to work was appraised as notable challenge and source of stress but was also perceived as ultimately facilitating recovery. Furthermore, a resource for one individual (such as the care and support provided by a partner) may constitute a demand on another (the challenge of providing that care).

Relationship dynamics: '*what I'm going through, she goes through as well*'

Appraisal and coping are also integral to Berg and Upchurch's (2007) model of couples facing chronic illness. However, they conceptualise appraisal and coping as dyadic in nature. For instance, the authors discuss shared stressor appraisals, influenced by the degree to which patients and partners perceive joint 'ownership' of the illness experience. In the current study, this was reflected in participants' language regarding cancer as a shared experience, as

illustrated by quotations in the results. Dyadic coping styles have been the focus of other research, such as avoidant coping compared with collaborative coping (Hagedoorn *et al.*, 2008). Such research has provided the rationale for interventions targeted at fostering dyadic coping (Randall & Bodenmann, 2009).

In-keeping with prior research (Segrin *et al.*, 2012; Morgan *et al.*, 2011), patients described their partners as a vital source of support and said that their own well-being and recovery was influenced by how their partner responded. Some participants echoed previous findings that the cancer experience ultimately strengthened their relationship (Dorval *et al.*, 2005; Gilbert *et al.*, 2010; Ka'Opua *et al.*, 2007; Tanner *et al.*, 2011). Nonetheless, participants also evidenced challenges placed on relationships during recovery from cancer.

By analysing contrast within couples, some disparity in beliefs and feelings about the patient's prognosis was apparent. Post-treatment fear of recurrence is well-recognised in patients (Simard *et al.*, 2010) but can also prove a significant difficulty for partners (Mellon *et al.*, 2007), even when the patient has an optimistic outlook, as this study affirms. There has been suggestion of involving caregivers in survivorship care planning as standard (Given *et al.*, 2011). The present study demonstrates some of the complexities around caregivers' attendance or involvement in follow up care. For example, the study illustrated that a patient and partner could come away from the same appointment with different understandings, and that couples can have differing expectations of follow-up care. Careful communication and a tailored approach are therefore important for successful caregiver involvement.

Healthcare services: '*leaving you to get on with it*'

Participants spoke of the importance attached to being informed and prepared for the longer-term impact after treatment (Bennion & Molassiotis, 2012). Their reported experiences commend the value of follow-up care (Lewis *et al.*, 2009). Disparity in couples' experiences of healthcare was apparent. This indicates that family support continues to be offered on an ad hoc rather than a systematic basis (Turner *et al.*, 2007). The results illustrated the alleviation of distress associated with the ongoing availability of healthcare support and with obtaining timely reassurance or advice. It also indicated the continuing uncertainty and difficulties that could result when participants experienced a lack of this type of support. These findings affirm existing evidence of both the adverse impact of poor communication and, conversely, the benefit of quality psychosocial care for alleviating distress and improving quality of life (Chochinov *et al.*, 2013; Street *et al.*, 2009). Chochinov and

colleagues (2013) therefore conducted focus groups of various healthcare providers with clinical experience in oncology, from which they developed an empirical model of therapeutic effectiveness in communication with patients. Aspects of this model were echoed in the present study findings. Specifically, the domains of therapeutic pacing and presence were reflected in participants' accounts of the value attached to healthcare professionals taking time, not only to provide information and answer questions but also to talk more informally, appreciating the personable manner with which care was delivered.

Other research has expounded on specific pathways by which clinician-patient communication can directly and indirectly impact on health outcomes (Street *et al.*, 2009). For instance, communication can affect the quality of medical decisions and suitability of treatment plans as well as access to needed care. In the present study, there were reported experiences where communication breakdown appeared to hinder timely and appropriate medical care. Conversely, some participants gave voice to the sense of reassurance and validation engendered by helpful encounters with healthcare staff, suggesting that good communication skills can indeed reduce negative and foster positive emotions (Street *et al.*, 2009). Communication can also affect trust and confidence in the clinician and healthcare system, and satisfaction with care (Hack *et al.*, 2005; Street *et al.*, 2009), which was also apparent from participants' narratives. Consequently, the importance of clinician communication has been recognised in the development of skills training programmes (Barth & Lannen, 2012; Moore *et al.*, 2009; Schofield *et al.*, 2008). However, patients have been found to perceive the quality of communication within consultations differently from clinicians or observers (Fagerlind *et al.*, 2012). Therefore, evaluation of these programmes should include patients' and caregivers' perceptions of their impact on clinicians' communication skills (Epstein *et al.*, 2010). It is not known whether communication skills training had been attended by any of the healthcare professionals working with the study participants. The findings indicate that there remains scope for improvement in this aspect of clinical care from the perspectives of patients and caregivers.

People hold differing preferences for a clinician's consulting style and for the level of patient involvement in decision making (Dowsett *et al.*, 2000). While the study findings suggested the importance of patient-centred communication, the complexity of defining and measuring this is acknowledged (Epstein *et al.*, 2005). Participants' narratives touched on all six aspects of patient-centered care outlined by Epstein and colleagues, namely: fostering a healing relationship, exchanging information, responding to emotions, managing uncertainty,

making decisions, and enabling self-management (Epstein *et al.*, 2010). In this study, information exchange and a therapeutic relationship with healthcare providers were highlighted in particular.

Methodological Considerations

Completion of the COREQ (Appendix 3) helped to ensure that consideration was given to the various domains, with explicit description of these provided in the reporting where appropriate. For instance, the interviewer, first analyst and co-analyst were identified and reflexivity was discussed (p.50-51). Similarly, the COREQ criteria guided reporting of the study design including theoretical approach, participant selection and data collection and analysis. Some information was not included in the main body of journal article due to constraints of the word limit. Including the completed COREQ as an appendix allowed this detail to be retained and reported in a standardised way, enabling readers to identify details about the methodology more readily. Further discussion of the size and heterogeneity of the sample and the process of determining data sufficiency is provided below.

Sample size in qualitative research is influenced by a number of factors including the homogeneity of the sample but also the type and depth of analysis. The process of dyadic analysis involves analysis of both the individuals separately as well as that of the dyad jointly. This lends greater depth, providing additional information or 'richness' of findings (Eisikovits & Koren, 2010). The sample size of ten participants comprising five dyads was comparable to other published studies employing qualitative dyadic analysis (6 dyads and 1 triad in Akeson *et al.*, 2007; 5 dyads in Cup *et al.*, 2011). A sample of ten participants has been found to be an adequate size within studies undertaking detailed thematic analysis of individuals' lived experience (Smith, 2008).

It is acknowledged that findings may have been influenced by heterogeneity within demographic variables such as age, employment status, duration of relationship and whether the couples were married or cohabiting. Also, treatment type was different for one patient who had received radiotherapy in addition to surgery and chemotherapy. The extent to which these variables impact on couples' post-treatment experiences could be explored in further research.

Nonetheless, a degree of homogeneity within the sample was established for certain variables of central importance to the research aims. All participants had experience relating

to colorectal cancer, a successful treatment outcome and were interviewed at a similar time post-treatment. All couples were in long-term, heterosexual relationships and were of similar cultural background and ethnic origin. The initial four couples interviewed were a relatively homogeneous group of older, retired couples who had been in a committed relationship for many years, which are common characteristics within the wider population of people affected by colorectal cancer. It was of interest to explore whether similar or contrasting themes would be described by a younger, working-age couple with a shorter duration of relationship. The fifth couple (see Table 2.1) was therefore purposefully sampled. Despite individual differences, there was notable congruence or 'replication' (Morse *et al.*, 2002) of the major themes which had been identified within the initial data analysis (relating to recovery, relationship dynamics and healthcare services). This lent support to the sufficiency of the data, suggesting that the diversity and detail of the findings were informative and robust enough to be pertinent to couples in the post-treatment stage following colorectal cancer. The first author decided to cease data collection at that point.

It has been argued that not only a lack of data but also an excess of it can be problematic for forming a coherent conclusion to qualitative data analysis (Mason, 2010). A balance is required to obtain enough data to address the research aims while minimising the acquisition of data which is superfluous or which cannot be used for the purposes of addressing the research question. An individual's lived experience is inherently unique. As such, it can be argued that the potential to acquire new information remains indefinitely within the process of exploring people's experiences. From this perspective, language describing data saturation as the continuation of data collection until reaching the point of 'redundancy', where 'nothing new is being added', (Bowen, 2008, p.140) can prove problematic. How saturation is defined and determined is a source of debate (Bowen, 2008). However, it can also be debated whether it is theoretically possible to achieve true saturation, whether it is practically feasible, and whether it is even necessary for the purpose of adequately addressing a research question (Dey, 1999).

Replication or repetition within the dataset is undoubtedly important and informative. However, exceptions ('deviant' or 'negative' cases) are also enlightening, reflecting individual differences and the uniqueness of human experience which are of central importance to the qualitative paradigm. While an absence of repetition and shared themes would indicate inadequate focus within the data collection process, complete homogeneity and the absence of exceptions or divergent views could indicate inadequate scope and a

narrow focus or 'tunnel vision'. Differences as well as commonalities in individuals' experiences are important in detailed exploration of a topic. The aim of the present study, therefore, was not to continue to collect and analyse data until no further novel information or different issues were raised. Rather, the study sought to continue to explore both individual differences and shared overarching themes in analysis of each interview.

The concept of sufficiency was adopted to guide data collection. The study did not purport to achieve 'saturation' with its implied exhaustive completeness (Dey, 1999). Purposeful sampling, data collection and analysis continued until enough data had been acquired to provide a rich body of information relevant to the research aims. Sufficiency was deemed to have been achieved at the point where the amount and detail of acquired data enabled elaboration of the thematic framework, with identification of overarching themes recurrent in the additional and final interviews, as well as enough detail to allow discussion of individual differences and nuances within the major themes. The dataset provided evidence for a detailed thematic and dyadic analysis considered to be instructive in relation to the main research aims. It is acknowledged that additional data may have provided additional insight into the wider topic of couples' post-treatment experiences. However, detailed analysis of additional data was not feasible within the resource constraints of the study. Nonetheless, the reported findings and framework were considered to be informative in their own right and as a guide for future research.

Thesis References (for entire portfolio)

- Adams, E., Boulton, M., Rose, P. W., Lund, S., Richardson, A., Wilson, S. *et al.* (2012). A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care. *Supportive Care in Cancer*, 20(11), 2785-2794.
- Akeson, N., Worth, A., & Sheikh, A. (2007). The psychosocial impact of anaphylaxis on young people and their parents. *Clinical & Experimental Allergy*, 37(8), 1213-1220.
- Altschuler, J. (1997). *Working with chronic illness: A family approach*. Basingstoke: Palgrave Macmillan.
- Anderson, K. O., Richman, S. P., Hurley, J., Palos, G., Valero, V., Mendoza, T. *et al.* (2002). Cancer pain management among underserved minority outpatients. *Cancer*, 94, 2295-2304.
- Bain, N. S. C., Campbell, N. C., Ritchie, L. D., & Cassidy, J. (2002). Striking the right balance in colorectal cancer care—a qualitative study of rural and urban patients. *Family Practice*, 19(4), 369-374.
- Barth, J., & Lannen, P. (2011). Efficacy of communication skills training courses in oncology: A systematic review and meta-analysis. *Annals of Oncology*, 22(5), 1030-1040.
- Beattie, S., & Lebel, S. (2011). The experience of caregivers of hematological cancer patients undergoing a hematopoietic stem cell transplant: A comprehensive literature review. *Psycho-Oncology*, 20(11), 1137-50.
- Beaver, K., Latif, S., Williamson, S., Procter, D., Sheridan, J., Heath, J. *et al.* (2010). An exploratory study of the follow-up care needs of patients treated for colorectal cancer. *Journal of Clinical Nursing*, 19(23-24), 3291-3300.
- Bennion, A. E., & Molassiotis, A. (2012). Qualitative research into the symptom experiences of adult cancer patients after treatments: A systematic review and meta-synthesis. *Supportive Care in Cancer*, 21(1), 9-25.
- Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, 133(6), 920-954.
- Bevans, M., & Stenberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA: The Journal of the American Medical Association*, 307(4), 398-403.
- Bevans, M., Wehrle, L., Prachenko, O., Soeken, K., Zabora, J., & Wallen, G. R. (2011). Distress screening in allogeneic hematopoietic stem cell (HSCT) caregivers and patients. *Psycho-Oncology*, 20(6), 615-622.
- Bidstrup, P. E., Johansen, C., & Mitchell, A. J. (2011). Screening for cancer-related distress: Summary of evidence from tools to programmes. *Acta Oncologica*, 50(2), 194-204.
- Birnie, K., Garland, S. N., & Carlson, L. E. (2010). Psychological benefits for cancer patients and their partners participating in mindfulness-based stress reduction (MBSR). *Psycho-Oncology*, 19(9), 1004-1009.
- Bishop, M. M., Curbow, B. A., Springer, S. H., Lee, J. A., & Wingard, J. R. (2011). Comparison of lasting life changes after cancer and BMT: Perspectives of long-term survivors and spouses. *Acta Oncologica*, 20(9), 926-934.
- Blum, K., & Sherman, D. W. (2010). Understanding the experience of caregivers: A focus on transitions. *Seminars in Oncology Nursing*, 26(4), 243-258.
- Booth, A. (2001, May). *Cochrane or cock-eyed? How should we conduct systematic reviews of qualitative research?* Paper presented at the meeting of the Qualitative Evidence-Based Practice Conference, Coventry University.
- Booth, A. (2006). "Brimful of starlite": Toward standards for reporting literature searches. *Journal of the Medical Library Association*, 94(4), 421-429.
- Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research*, 8(1), 137-152.

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Broughton, M., Bailey, J., & Linney, J. (2004). How can experiences of patients and carers influence the clinical care of large bowel cancer? *European Journal of Cancer Care*, 13(4), 318-327.
- Brunton, G., Oliver, S., Oliver, K., & Lorenc, T. (2006). *A synthesis of research addressing children's young people's and parents' views of walking and cycling for transport*. London: Evidence for Policy and Practice Information and Coordinating Centre, Social Science Research Unit.
- Bruun, P., Pedersen, B. D., Osther, P. J., & Wagner, L. (2011). The lonely female partner: A central aspect of prostate cancer. *Urologic Nursing*, 31(5), 294-299.
- Buckner, L., & Yeandle, S. (2011). *Valuing carers 2011; Calculating the value of carers' support*. London: Carers UK.
- Burridge, L., Mitchell, G., Jiwa, M., & Girgis, A. (2011). Consultation etiquette in general practice: A qualitative study of what makes it different for lay cancer caregivers. *BMC Family Practice*, 12(1), 110-118.
- Butow, P. N., Phillips, F., Schweder, J., White, K., Underhill, C., & Goldstein, D. (2012). Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: A systematic review. *Supportive Care in Cancer*, 20(1), 1-22.
- Cagle, C. S., & Wells, J. N. (2010). Healthcare literacy. *Clinical Journal of Oncology Nursing*, 14(1), E1-E9.
- Cancer Research UK. (2012). Bowel cancer survival statistics. Retrieved 17 February, 2013, from <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/survival/>.
- Carroll, C., Booth, A., & Cooper, K. (2011). A worked example of "best fit" framework synthesis: A systematic review of views concerning the taking of some potential chemopreventive agents. *BMC Medical Research Methodology*, 11(1), 29-38.
- Céilleachair, A., Costello, L., Finn, C., Timmons, A., Fitzpatrick, P., Kapur, K. *et al.* (2012). Inter-relationships between the economic and emotional consequences of colorectal cancer for patients and their families: A qualitative study. *BMC Gastroenterology*, 12(1), 62-72.
- Centre for Reviews and Dissemination (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York: University of York Centre for Reviews and Dissemination
- Chochinov, H. M., McClement, S. E., Hack, T. F., McKeen, N. A., Rach, A. M., Gagnon, P. *et al.* (2013). Health care provider communication: An empirical model of therapeutic effectiveness. *Cancer*, 119(9), 1706-1713.
- Chung, C., & Hwang, E. (2012). Couples' experiences of breast cancer in Korea: A descriptive qualitative study. *Cancer Nursing*, 35(3), 211-220.
- Couper, J., Bloch, S., Love, A., Macvean, M., Duchesne, G. M., & Kissane, D. (2006). Psychosocial adjustment of female partners of men with prostate cancer: A review of the literature. *Psycho-Oncology*, 15(11), 937-953.
- Denlinger, C. S., & Barsevick, A. M. (2009). The challenges of colorectal cancer survivorship. *Journal of the National Comprehensive Cancer Network*, 7(8), 883-894.
- Department of Health (2012). *Improving Outcomes: A Strategy for Cancer - Second Annual Report*. London: Department of Health
- Department of Health (2013). *Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)*. London: Department of Health
- Dey, I. (1999). *Grounding grounded theory*. San Diego: Academic Press.
- Diamond, J. (1998). *C: Because Cowards Get Cancer Too*. London: Vermilion.
- Dixon-Woods, M. (2011). Using framework-based synthesis for conducting reviews of qualitative studies. *BMC Medicine*, 9, 39-40.

- Dixon-Woods, M., Bonas, S., Booth, A., Jones, D. R., Miller, T., Sutton, A. J. *et al.* (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research*, 6(1), 27-44.
- Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B. *et al.* (2007). Appraising qualitative research for inclusion in systematic reviews: A quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy*, 12(1), 42-47.
- Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care*, 13(3), 223-225.
- Dorval, M., Guay, S., Mondor, M., Mâsse, B., Falardeau, M., Robidoux, A. *et al.* (2005). Couples who get closer after breast cancer: Frequency and predictors in a prospective investigation. *Journal of Clinical Oncology*, 23(15), 3588-3596.
- Dowsett, S. M., Saul, J. L., Butow, P. N., Dunn, S. M., Boyer, M. J., Findlow, R. *et al.* (2000). Communication styles in the cancer consultation: Preferences for a patient-centred approach. *Psycho-Oncology*, 9(2), 147-156.
- Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research*, 20(2), 148-158.
- Dunn, J., Lynch, B., Rinaldis, M., Pakenham, K., McPherson, L., Owen, N. *et al.* (2005). Dimensions of quality of life and psychosocial variables most salient to colorectal cancer patients. *Psycho-Oncology*, 15(1), 20-30.
- Eisikovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*, 20(12), 1642-1655.
- Emslie, C., Browne, S., Macleod, U., Rozmovits, L., Mitchell, E., & Ziebland, S. (2009). 'Getting through' not 'going under': A qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social Science & Medicine*, 68(6), 1169-1175.
- Epstein, R. M., Fiscella, K., Lesser, C. S., & Stange, K. C. (2010). Why the nation needs a policy push on patient-centered health care. *Health Affairs*, 29(8), 1489-1495.
- Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L. *et al.* (2005). Measuring patient-centered communication in patient-physician consultations: Theoretical and practical issues. *Social Science & Medicine*, 61(7), 1516-1528.
- Fagerlind, H., Kettis, A., Bergstrom, I., Glimelius, B., & Ring, L. (2012). Different perspectives on communication quality and emotional functioning during routine oncology consultations. *Patient Education and Counseling*, 88(1), 16-22.
- Fallowfield, L., & Jenkins, V. (1999). Effective communication skills are the key to good cancer care. *European Journal of Cancer*, 35(11), 1592-1597.
- Fillion, L., De Serres, M., Lapointe-Goupil, R., Bairati, I., Gagnon, P., Deschamps, M. *et al.* (2006). Implementing the role of patient-navigator nurse at a university hospital centre. *Canadian Oncology Nursing Journal*, 16(1), 5-10.
- Finocchiaro, C. Y., Botturi, A., Lamperti, E., Gauri, S., Petruzzi, A., Simonetti, G. *et al.* (2011). Privacy-Solidarity conflict: The communication with the support group. *Neurological Sciences*, 32(2), 225-227.
- Fletcher, B. S., Miaskowski, C., Given, B., & Schumacher, K. (2012). The cancer family caregiving experience: An updated and expanded conceptual model. *European Journal of Oncology Nursing*, 16(4), 387-398.
- Gaugler, J. E., Linder, J., Given, C. W., Kataria, R., Tucker, G., & Regine, W. F. (2009). Family cancer caregiving and negative outcomes: The direct and mediational effects of psychosocial resources. *Journal of Family Nursing*, 15(4), 417-444.
- Gilbert, E., Ussher, J. M., & Hawkins, Y. (2009). Accounts of disruptions to sexuality following cancer: The perspective of informal carers who are partners of a person with cancer. *Health*, 13(5), 523-541.

- Gilbert, E., Ussher, J. M., & Perz, J. (2010). Renegotiating sexuality and intimacy in the context of cancer: The experiences of carers. *Archives of Sexual Behavior*, 39(4), 998-1009.
- Girgis, A., Lambert, S. D., McElduff, P., Bonevski, B., Lecathelinais, C., Boyes, A. *et al.* (2013). Some things change, some things stay the same: A longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psycho-Oncology*, 22(7), 1557-1564.
- Given, B. A., Given, C. W., & Sherwood, P. R. (2012). Family and caregiver needs over the course of the cancer trajectory. *The Journal of Supportive Oncology*, 10(2), 57-64.
- Given, B. A., Sherwood, P., & Given, C. W. (2011). Support for caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiology, Biomarkers & Prevention*, 20(10), 2015-2021.
- Grant, M., McMullen, C. K., Altschuler, A., Mohler, M. J., Hornbrook, M. C., Herrinton, L. J. *et al.* (2011). Gender differences in quality of life among long-term colorectal cancer survivors with ostomies. *Oncology Nursing Forum*, 38(5), 587-596.
- Green, H. J., Wells, D. J., & Laakso, L. (2011). Coping in men with prostate cancer and their partners: A quantitative and qualitative study. *European Journal of Cancer Care (England)*, 20(2), 237-247.
- Green, J., & Thorogood, N. (2004). *Qualitative Methods for Health Research*. London: Sage Publications.
- Hack, T. F., Degner, L. F., & Parker, P. A. (2005). The communication goals and needs of cancer patients: A review. *Psycho-Oncology*, 14(10), 831-47.
- Hagedoorn, M., Kreicbergs, U., & Appel, C. (2011). Coping with cancer: The perspective of patients' relatives. *Acta Oncologica*, 50(2), 205-211.
- Hall, S., Gray, N., Browne, S., Ziebland, S., & Campbell, N. C. (2012). A qualitative exploration of the role of primary care in supporting colorectal cancer patients. *Supportive Care in Cancer*, 20(12), 3071-3078.
- Harding, R., & Higginson, I. J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17(1), 63-74.
- Harrison, S. E., Watson, E. K., Ward, A. M., Khan, N. F., Turner, D., Adams, E. *et al.* (2012). Cancer survivors' experiences of discharge from hospital follow-up. *European Journal of Cancer Care*, 21(3), 390-397.
- Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the evidence: Reviewing disparate data systematically. *Qualitative Health Research*, 12(9), 1284-1299.
- Hodgkinson, K., Butow, P., Hobbs, K. M., & Wain, G. (2007). After cancer: The unmet supportive care needs of survivors and their partners. *Journal of Psychosocial Oncology*, 25(4), 89-104.
- Hodgson, T. (2006). Oesophageal cancer: Experiences of patients and their partners. *British Journal of Nursing*, 1157-1160.
- Hoga, L. A. K., Mello, D. S., & Dias, A. F. (2008). Psychosocial perspectives of the partners of breast cancer patients treated with a mastectomy: An analysis of personal narratives. *Cancer Nursing*, 31(4), 318-325.
- Hopkinson, J. B., Brown, J. C., Okamoto, I., & Addington-Hall, J. M. (2012). The effectiveness of patient-family carer (couple) intervention for the management of symptoms and other health-related problems in people affected by cancer: A systematic literature search and narrative review. *Journal of Pain and Symptom Management*, 43(1), 111-142.
- Hou, W. K., Lam, W. W. T., & Fielding, R. (2009). Adaptation process and psychosocial resources of Chinese colorectal cancer patients undergoing adjuvant treatment: A qualitative analysis. *Psycho-Oncology*, 18(9), 936-944.
- Houldin, A. D. (2007). A qualitative study of caregivers' experiences with newly diagnosed advanced colorectal cancer. *Oncology Nursing Forum*, 34(2), 323-330.

- Houldin, A. D., & Lewis, F. M. (2006). Salvaging their normal lives: A qualitative study of patients with recently diagnosed advanced colorectal cancer. *Oncology Nursing Forum*, 33(4), 719-725.
- Hubbard, G., Kidd, L., & Kearney, N. (2010). Disrupted lives and threats to identity: The experiences of people with colorectal cancer within the first year following diagnosis. *Health*, 14(2), 131-146.
- Hudson, P., Aranda, S., & McMurray, N. (2002). Intervention development for enhanced lay palliative caregiver support—the use of focus groups. *European Journal of Cancer Care*, 11(4), 262-270.
- Jansen, L., Koch, L., Brenner, H., & Arndt, V. (2010). Quality of life among long-term (\geq 5 years) colorectal cancer survivors—systematic review. *European Journal of Cancer*, 46(16), 2879-2888.
- Jones, M. L. (2004). Application of systematic review methods to qualitative research: Practical issues. *Journal of Advanced Nursing*, 48(3), 271-278.
- Jones, M. L. (2005). Role development and effective practice in specialist and advanced practice roles in acute hospital settings: Systematic review and meta-synthesis. *Journal of Advanced Nursing*, 49(2), 191-209.
- Judd, F., Jackson, H., Komiti, A., Murray, G., Fraser, C., Grieve, A. *et al.* (2006). Help-Seeking by rural residents for mental health problems: The importance of agrarian values. *Australian and New Zealand Journal of Psychiatry*, 40(9), 769-776.
- Ka'opua, L. S. I., Gotay, C. C., & Boehm, P. S. (2007). Spiritually based resources in adaptation to long-term prostate cancer survival: Perspectives of elderly wives. *Health & Social Work*, 32(1), 29-39.
- Karekla, M., & Constantinou, M. (2010). Religious coping and cancer: Proposing an acceptance and commitment therapy approach. *Cognitive and Behavioral Practice*, 17(4), 371-381.
- Kendall, M., Murray, S. A., Carduff, E., Worth, A., Harris, F., Lloyd, A. *et al.* (2009). Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ*, 340, 196-199.
- Kidd, L., Forbat, L., Kochen, M., & Kearney, N. (2011). The supportive care needs of carers of people affected by cancer stationed in British Forces Germany. *European Journal of Cancer Care (England)*, 20(2), 212-219.
- Kim, Y., Spillers, R. L., & Hall, D. L. (2012). Quality of life of family caregivers 5 years after a relative's cancer diagnosis: Follow-up of the national quality of life survey for caregivers. *Psycho-Oncology*, 21(3), 273-281.
- Knott, V., Turnbull, D., Olver, I., & Winefield, A. (2012). A grounded theory approach to understand the cancer-coping process. *British Journal of Health Psychology*, 17(3), 551-564.
- Lambert, S. D., Harrison, J. D., Smith, E., Bonevski, B., Carey, M., Laws, C. *et al.* (2012). The unmet needs of partners and caregivers of adults diagnosed with cancer: A systematic review. *BMJ Supportive & Palliative Care*, 2(3), 224-230.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing Company.
- Lee, J., & Bell, K. (2011). The impact of cancer on family relationships among Chinese patients. *Journal of Transcultural Nursing*, 22(3), 225-234.
- Lethborg, C. E., Kissane, D., & Burns, W. I. (2003). 'It's not the easy part': The experience of significant others of women with early stage breast cancer, at treatment completion. *Social Work in Health Care*, 37(1), 63-85.
- Lewis, F. M. (2006). The effects of cancer survivorship on families and caregivers: More research is needed on long-term survivors. *The American Journal of Nursing*, 106, 20-25.

- Lewis, R. A., Neal, R. D., Hendry, M., France, B., Williams, N. H., Russell, D. *et al.* (2009). Patients' and healthcare professionals' views of cancer follow-up: Systematic review. *The British Journal of General Practice*, 59(564), e248.
- Li, Q. P., Mak, Y. W., & Loke, A. Y. (2012). Spouses' experience of caregiving for cancer patients: A literature review. *International Nursing Review*, 60(2), 178-187.
- Lohfeld, L., Brazil, K., & Willison, K. (2007). Continuity of care for advanced cancer patients: Comparing the views of spousal caregivers in Ontario, Canada, to Dumont *et al.*'s theoretical model. *Journal of Palliative Care*, 23, 117-26.
- Lopez, V., Copp, G., & Molassiotis, A. (2012). Male caregivers of patients with breast and gynecologic cancer: Experiences from caring for their spouses and partners. *Cancer Nursing*, 35(6), 402-10.
- Mason, M. (2010). Sample size and saturation in phd studies using qualitative interviews. *Forum: Qualitative Social Research*, 11(3), Art. 8.
- Maughan, K., Heyman, B., & Matthews, M. (2002). In the shadow of risk.: How men cope with a partner's gynaecological cancer. *International Journal of Nursing Studies*, 39(1), 27-34.
- Mayer, D. K., Gerstel, A., Leak, A. N., & Smith, S. K. (2012). Patient and provider preferences for survivorship care plans. *Journal of Oncology Practice*, 8(4), e80-e86.
- McCaughan, E., Parahoo, K., & Prue, G. (2011). Comparing cancer experiences among people with colorectal cancer: A qualitative study. *Journal of Advanced Nursing*, 67(12), 2686-2695.
- McCaughan, E., Prue, G., Parahoo, K., McIlpatrick, S., & McKenna, H. (2012). Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer after chemotherapy treatment: A qualitative longitudinal study. *Psycho-Oncology*, 21(1), 64-71.
- McMullen, C. K., Hornbrook, M. C., Grant, M., Baldwin, C. M., Wendel, C. S., Mohler, M. J. *et al.* (2008). The greatest challenges reported by long-term colorectal cancer survivors with stomas. *The Journal of Supportive Oncology*, 6(4), 175-182.
- Mellon, S., Kershaw, T. S., Northouse, L. L., & Freeman-Gibb, L. (2007). A family-based model to predict fear of recurrence for cancer survivors and their caregivers. *Psycho-Oncology*, 16(3), 214-223.
- Mellon, S., Northouse, L. L., & Weiss, L. K. (2006). A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nursing*, 29(2), 120-131.
- Meyler, D., Stimpson, J. P., & Peek, M. K. (2007). Health concordance within couples: A systematic review. *Social Science & Medicine*, 64(11), 2297-2310.
- Mitchell, G., Girgis, A., Jiwa, M., Sibbritt, D., & Burridge, L. (2010). A gp caregiver needs toolkit versus usual care in the management of the needs of caregivers of patients with advanced cancer: A randomized controlled trial. *Trials*, 11(1), 115.
- Mitschke, D. B. (2008). Cancer in the family: Review of the psychosocial perspectives of patients and family members. *Journal of Family Social Work*, 11(2), 166-184.
- Moore, A., Grime, J., Campbell, P., & Richardson, J. (2013). Troubling stoicism: Sociocultural influences and applications to health and illness behaviour. *Health*, 17(2), 159-173.
- Moore, P. M., Wilkinson, S. S. M., & Rivera Mercado, S. (2009). Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database of Systematic Reviews*, 1, 1-21.
- Morgan, M. A., Small, B. J., Donovan, K. A., Overcash, J., & McMillan, S. (2011). Cancer patients with pain: The spouse/partner relationship and quality of life. *Cancer Nursing*, 34(1), 13-23.
- Morse, J. M., Barret, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 1-19.

- Morton, K. H., & Goodacre, L. (2008). An exploration of the impact of home enteral tube feeding on the eating habits of the partners of adults receiving home enteral tube feeding. *Journal of Human Nutrition and Dietetics*, 21(4), 397-397.
- Murray, G., Judd, F., Jackson, H., Fraser, C., Komiti, A., Pattison, P. *et al.* (2008). Big boys don't cry: An investigation of stoicism and its mental health outcomes. *Personality and Individual Differences*, 44(6), 1369-1381.
- Murray, S. A., Kendall, M., Boyd, K., Grant, L., Highet, G., & Sheikh, A. (2010). Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: Secondary analysis of serial qualitative interviews. *BMJ*, 340, c2581-c2581.
- Nanton, V., Docherty, A., Meystre, C., & Dale, J. (2009). Finding a pathway: Information and uncertainty along the prostate cancer patient journey. *British Journal of Health Psychology*, 14(3), 437-458.
- Ness, R. M., Holmes, A., Klein, R., Greene, J., & Dittus, R. (1998). Outcome states of colorectal cancer: Identification and description using patient focus groups. *The American Journal of Gastroenterology*, 93(9), 1491-1497.
- Norlyk, A., & Martinsen, B. (2012). The extended arm of health professionals? Relatives' experiences of patient's recovery in a fast-track programme. *Journal of Advanced Nursing*, 69(8), 1737-1746.
- Northouse, L., Williams, A. L., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology*, 30(11), 1227-1234.
- Northouse, L. L., Schafer, J. A., Tipton, J., & Metivier, L. (1999). The concerns of patients and spouses after the diagnosis of colon cancer: A qualitative analysis. *Journal of Wound, Ostomy and Continence Nursing*, 26(1), 8-17.
- Northouse, L. L. (2005). Helping families of patients with cancer. *Oncology Nursing Forum*, 32(4), 743-750.
- O'Reilly, M., & Parker, N. (2013). 'Unsatisfactory saturation': A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13(2), 190-197.
- Office for National Statistics (2012). *Cancer incidence and mortality in the united kingdom, 2008-10*. London: Office for National Statistics.
- Ohlsson-Nevo, E., Andershed, B., Nilsson, U. G., & Anderzen-Carlsson, A. (2012). Finding a wider horizon: Experiences of being a next-of-kin of a person suffering from colorectal cancer as told after having participated in a psychoeducational program. *European Journal of Oncology Nursing*, 17(3), 324-330.
- Ohlsson-Nevo, E., Andershed, B., Nilsson, U., & Anderzén-Carlsson, A. (2011). Life is back to normal and yet not—partners' and patient's experiences of life of the first year after colorectal cancer surgery. *Journal of Clinical Nursing*, 21(3-4), 555-563.
- Oliver, S., Harden, A., Rees, R., Shepherd, J., Brunton, G., Garcia, J. *et al.* (2005). An emerging framework for including different types of evidence in systematic reviews for public policy. *Evaluation*, 11(4), 428-446.
- Oliver, S. R., Rees, R. W., Clarke-Jones, L., Milne, R., Oakley, A. R., Gabbay, J. *et al.* (2008). A multidimensional conceptual framework for analysing public involvement in health services research. *Health Expectations*, 11(1), 72-84.
- Olson, R. (2009). *Carers of cancer patients: understanding their support service needs*. Acton ACT: Cancer Council ACT
- Patterson, J. M., Holm, K. E., & Gurney, J. G. (2004). The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology*, 13(6), 390-407.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks: Sage Publications.

- Persson, E., Severinsson, E., & Hellström, A. L. (2004). Spouses' perceptions of and reactions to living with a partner who has undergone surgery for rectal cancer resulting in a stoma. *Cancer Nursing*, 27(1), 85-90.
- Persson, E., & Hellström, A. L. (2002). Experiences of Swedish men and women 6 to 12 weeks after ostomy surgery. *Journal of Wound Ostomy & Continence Nursing*, 29(2), 103-108.
- Petticrew, M., & Roberts, H. (2006). *Systematic reviews in the social sciences: A practical guide*. Oxford: Blackwell Publishing.
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives. *European Journal of Cancer*, 39(11), 1517-1524.
- Pope, C., & Mays, N. (2006). *Qualitative research in health care* (3rd ed.). Oxford: Blackwell Publishing.
- Public Health Research Unit (2002). *Critical Appraisal Skills Programme (CASP) 10 questions to help you make sense of qualitative research*. Oxford: Public Health Research Unit
- Ramfelt, E., Severinsson, E., & Lützén, K. (2002). Attempting to find meaning in illness to achieve emotional coherence: The experiences of patients with colorectal cancer. *Cancer Nursing*, 25(2), 141-149.
- Randall, A. K., & Bodenmann, G. (2009). The role of stress on close relationships and marital satisfaction. *Clinical Psychology Review*, 29(2), 105-115.
- Ritchie, J., & Lewis, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. London, UK: Sage Publications.
- Röing, M., Hirsch, J. M., & Holmström, I. (2008). Living in a state of suspension—a phenomenological approach to the spouse's experience of oral cancer. *Scandinavian Journal of Caring Sciences*, 22(1), 40-47.
- Rolland, J. S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process*, 26(2), 203-221.
- Rolland, J. S. (1999). Parental illness and disability: A family systems framework. *Journal of Family Therapy*, 21(3), 242-266.
- Rozmovits, L., Rose, P., & Ziebland, S. (2004). In the absence of evidence, who chooses? A qualitative study of patients' needs after treatment for colorectal cancer. *Journal of Health Services Research & Policy*, 9(3), 159-164.
- Rusinak, R. L., & Murphy, J. F. (1995). Elderly spousal caregivers: Knowledge of cancer care, perceptions of preparedness, and coping strategies. *Journal of Gerontological Nursing*, 21(3), 33-41.
- Sabo, B., McLeod, D., & Couban, S. (2013). The experience of caring for a spouse undergoing hematopoietic stem cell transplantation: Opening pandora's box. *Cancer Nursing*, 36(1), 29-40.
- Sahay, T. B., Gray, R. E., & Fitch, M. (2001). A qualitative study of patient perspectives on colorectal cancer. *Cancer Practice*, 8(1), 38-44.
- Sandén, I., & Söderhamn, O. (2009). Experiences of living in a disrupted situation as partner to a man with testicular cancer. *American Journal of Men's Health*, 3(2), 126-133.
- Sanders, S., Pedro, L. W., Bantum, E. O. C., & Galbraith, M. E. (2006). Couples surviving prostate cancer: Long-term intimacy needs and concerns following treatment. *Clinical Journal of Oncology Nursing*, 10(4), 503-508.
- Schmidt, S. D., Blank, T. O., Bellizzi, K. M., & Park, C. L. (2012). The relationship of coping strategies, social support, and attachment style with post-traumatic growth in cancer survivors. *Journal of Health Psychology*, 17(7), 1033-1040.
- Schofield, N. G., Green, C., & Creed, F. (2008). Communication skills of health-care professionals working in oncology—can they be improved? *European Journal of Oncology Nursing*, 12(1), 4-13.

- Schumacher, K. L., Stewart, B. J., Archbold, P. G., Dodd, M. J., & Dibble, S. L. (2000). Family caregiving skill: Development of the concept. *Research in Nursing & Health*, 23(3), 191-203.
- Segrin, C., Badger, T. A., & Harrington, J. (2012). Interdependent psychological quality of life in dyads adjusting to prostate cancer. *Health Psychology*, 31(1), 70-79.
- Seymour, K. C., Addington-Hall, J., Lucassen, A. M., & Foster, C. L. (2010). What facilitates or impedes family communication following genetic testing for cancer risk? A systematic review and meta-synthesis of primary qualitative research. *Journal of Genetic Counseling*, 19(4), 330-342.
- Sherwood, P., Hricik, A., Donovan, H., Bradley, S. E., Given, B. A., Bender, C. M. *et al.* (2011). Changes in caregiver perceptions over time in response to providing care for a loved one with a primary malignant brain tumor. *Oncology Nursing Forum*, 38(2), 149-155.
- Simard, S., Savard, J., & Ivers, H. (2010). Fear of cancer recurrence: Specific profiles and nature of intrusive thoughts. *Journal of Cancer Survivorship*, 4, 361-71.
- Simpson, M. F., & Whyte, F. (2006). Patients' experiences of completing treatment for colorectal cancer in a Scottish district general hospital. *European Journal of Cancer Care*, 15(2), 172-182.
- Sinfield, P., Baker, R., Ali, S., & Richardson, A. (2012). The needs of carers of men with prostate cancer and barriers and enablers to meeting them: A qualitative study in england. *European Journal of Cancer Care*, 21(4), 527-534.
- Singh, S. P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S. *et al.* (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *The British Journal of Psychiatry*, 197(4), 305-312.
- Sjovall, K., Gunnars, B., Olsson, H., & Thome, B. (2011). Experiences of living with advanced colorectal cancer from two perspectives - inside and outside. *European Journal of Oncology Nursing*, 15(5), 390-397.
- Smith, J. A. (2008). *Qualitative psychology: A practical guide to research methods*. London: Sage Publications
- Steginga, S. K., Campbell, A., Ferguson, M., Beeden, A., Walls, M., Cairns, W. *et al.* (2008). Socio-Demographic, psychosocial and attitudinal predictors of help seeking after cancer diagnosis. *Psycho-Oncology*, 17(10), 997-1005.
- Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 19(10), 1013-1025.
- Street, A. F., Couper, J. W., Love, A. W., Bloch, S., Kissane, D. W., & Street, B. C. (2010). Psychosocial adaptation in female partners of men with prostate cancer. *European Journal of Cancer Care (England)*, 19(2), 234-242.
- Street, R. L., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*, 74(3), 295-301.
- Suri, H. (2011). Purposeful sampling in qualitative research synthesis. *Qualitative Research Journal*, 11(2), 63-75.
- Swanberg, J. E. (2006). Making it work: Informal caregiving, cancer, and employment. *Journal of Psychosocial Oncology*, 24(3), 1-18.
- Szczepura, A., Price, C., & Gumber, A. (2008). Breast and bowel cancer screening uptake patterns over 15 years for UK South Asian ethnic minority populations, corrected for differences in socio-demographic characteristics. *BMC Public Health*, 8, 346-361.
- Tanner, T., Galbraith, M., & Hays, L. (2011). From a woman's perspective: Life as a partner of a prostate cancer survivor. *Journal of Midwifery & Womens Health*, 56(2), 154-160.
- Taylor, C. (2001). Patients' experiences of 'feeling on their own' following a diagnosis of colorectal cancer: A phenomenological approach. *International Journal of Nursing Studies*, 38(6), 651-661.

- Taylor, C., Richardson, A., & Cowley, S. (2010). Restoring embodied control following surgical treatment for colorectal cancer: A longitudinal qualitative study. *International Journal of Nursing Studies*, 47(8), 946-956.
- The Scottish Government (2010). *The Healthcare Quality Strategy for NHS Scotland*. Edinburgh: The Scottish Government.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45-55.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
- Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837-851.
- Trivedi, P., & Wykes, T. (2002). From passive subjects to equal partners: Qualitative review of user involvement in research. *The British Journal of Psychiatry*, 181(6), 468-472.
- Trudeau-Hern, S., & Daneshpour, M. (2012). Cancer's impact on spousal caregiver health: A qualitative analysis in grounded theory. *Contemporary Family Therapy*, 34(4), 534-554.
- Ussher, J. M., & Perz, J. (2010). Gender differences in self-silencing and psychological distress in informal cancer carers. *Psychology of Women Quarterly*, 34(2), 228-242.
- Wagstaff, G. F., & Rowledge, A. M. (1995). Stoicism: Its relation to gender, attitudes toward poverty, and reactions to emotive material. *The Journal of Social Psychology*, 135(2), 181-184.
- Waldron, E. A., Janke, E. A., Bechtel, C. F., Ramirez, M., & Cohen, A. (2012). A systematic review of psychosocial interventions to improve cancer caregiver quality of life. *Psycho-Oncology*, 22(6), 1200-1207.
- Walker, R. B., & Luszcz, M. A. (2009). The health and relationship dynamics of late-life couples: A systematic review of the literature. *Ageing and Society*, 29(03), 455-480.
- Walsh, D., & Downe, S. (2005). Meta-Synthesis method for qualitative research: A literature review. *Journal of Advanced Nursing*, 50(2), 204-211.
- Walsh, D., & Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*, 22(2), 108-119.
- Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process*, 42(1), 1-18.
- Whyte, F., & Smith, L. (1997). A literature review of adolescence and cancer. *European Journal of Cancer Care*, 6(2), 137-146.
- Yong, H. H., Gibson, S. J., & Horne, D. J. L. (2001). Development of a pain attitudes questionnaire to assess stoicism and cautiousness for possible age differences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 56(5), 279-284.
- Yosha, A. M., Carroll, J. K., Hendren, S., Salamone, C. M., Sanders, M., Fiscella, K. et al. (2011). Patient navigation from the paired perspectives of cancer patients and navigators: A qualitative analysis. *Patient Education and Counseling*, 82(3), 396-401.
- Zahlis, E. H., & Shands, M. E. (1993). The impact of breast cancer on the partner 18 months after diagnosis. *Seminars in Oncology Nursing*, 9(2), 83-87.

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Appendix 1. Eligible studies not sampled for review

Study	Reason not included in synthesis
Bishop et al., 2011 ¹	Methodology: insufficient reporting of qualitative data on partners' experiences
Bruun et al., 2011 ¹	Topic not directly relevant: focus on incurable cancer
Burrige et al., 2011 ²	Topic not directly relevant: focus on medical consultation etiquette
Cagle & Wells, 2010 ¹	Topic not directly relevant: focus on literacy and learning needs
Céilleachair et al., 2012 ²	Topic not directly relevant: focus on economic consequences
Fillion et al., 2006 ¹	Topic not directly relevant: focus on healthcare professional role and service delivery
Finocchiaro et al., 2011 ¹	Topic not directly relevant: focus on support groups
Green et al., 2011 ¹	Methodology: insufficient reporting of qualitative data on partners' experiences
Hodgkinson et al., 2007 ²	Methodology: insufficient reporting of qualitative data on partners' experiences
Hodgson, 2006 ¹	Methodology: insufficient reporting of qualitative data on partners' experiences
Kidd et al., 2011 ¹	Topic not directly relevant: focus on British forces environment
Lohfeld et al., 2007 ¹	Topic not directly relevant: focus on healthcare service delivery
Maughan et al., 2012 ²	Methodology: partners' results not clearly reported separately from patients' results
Morton & Goodacre, 2008 ¹	Topic not directly relevant: focus on tube feeding
Nanton et al., 2009 ²	Topic not directly relevant: focus on informational needs
Rusinak & Murphy, 1995 ¹	Topic not directly relevant: focus on knowledge of cancer
Sanders et al., 2006 ²	Methodology: insufficient reporting of qualitative data on partners' experiences
Schumacher et al., 2006 ¹	Topic not directly relevant: focus on skill acquisition
Swanberg, 2006 ²	Topic not directly relevant: focus on work-related issues
Trudeau-Hern & Daneshpour, 2012 ¹	Topic not directly relevant: focus on physical health outcomes
Ussher & Perz, 2010 ¹	Topic not directly relevant: focus on gender differences and self-silencing

¹ denotes studies identified by electronic database search; ² denotes studies identified by handsearch

Appendix 2. Contribution to themes by study

	Patient-Caregiver Relationship				Cancer Trajectory				Contextual Factors			
	Communication		Cohesion		Transitions		Gradual Changes		Healthcare System		Culture & Belief Systems	
	Barriers	Facilitators	Barriers	Facilitators	Barriers	Facilitators	Barriers	Facilitators	Barriers	Facilitators	Barriers	Facilitators
1	✓		✓		✓	✓			✓	✓	✓	
2	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	
3				✓	✓	✓		✓	✓	✓		✓
4		✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
5			✓		✓	✓	✓	✓		✓	✓	
6	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓
7	✓		✓		✓	✓	✓	✓	✓	✓	✓	
8	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	
9	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓
10	✓		✓		✓		✓			✓		

1: Adams *et al.*, 2012; 2: Gilbert *et al.*, 2009, 2010; 3: Hoga *et al.*, 2008; 4: Ka'opua *et al.*, 2007; 5: Lopez *et al.*, 2012; 6: Ohlsson-Nevo *et al.*, 2011; 7: Persson *et al.*, 2004; 8: Street *et al.*, 2010; 9: Tanner *et al.*, 2011; 10: Zalis & Shands, 1993.

Appendix 3. Methodology outlined according to Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong *et al.*, 2007)

Domain 1: Research team and reflexivity	
Personal Characteristics	
1. Interviewer	NW
2. Credentials	BSc Psychology, undertaking Doctorate in Clinical Psychology
3. Occupation	Trainee Clinical Psychologist
4. Gender	Female
5. Experience and training	Clinical and research experience in psychology (>7 years)
Relationship with participants	
6. Relationship established	No relationship established prior to study commencement
7. Participant knowledge of the interviewer	Participants were informed that the research was to fulfill the requirements for a Doctorate in Clinical Psychology and to further understanding of couples' experiences of services post-treatment (Participant Information Sheet available on request). Participants were informed that their participation would not affect the standard of care they received.
8. Interviewer characteristics	The interviewer (NW) was a psychologist and employee of the healthcare services discussed in interview, but not a member of the participants' direct clinical team. To reduce the risk of researcher bias, the co-author and service user/caregiver consultation group provided alternative viewpoints to the researcher's.
Domain 2: Study design	
Theoretical framework	
9. Methodological orientation and Theory	Framework Analysis Inductive (data-driven), semantic (dealing with explicit meanings within the data), realist/essentialist (language is considered a direct reflection of meaning and experience)
Participant selection	
10. Sampling	Purposeful
11. Method of approach	Telephone
12. Sample size	10 participants (5 couples)
13. Non-participation	n=7 declined to participate; stated reasons: too busy (n=4), unwell (n=1), hard of hearing (n=1), not interested (n=1) n=0 dropped out

Setting

14. Setting of data collection	Hospital clinic (n=6) or participant's home (n=4), according to participant's preference
15. Presence of non-participants	No one else present apart from the participant and researcher
16. Description of sample	Provided in Table 2.1

Data collection

17. Interview guide	Semi-structured interview schedule provided in Appendix 4, developed in collaboration with academic and clinical supervisors, as well as the service user and caregiver consultation group
18. Repeat interviews	None
19. Audio/visual recording	Audio recording
20. Field notes	Reflective notes made after each interview and during analysis
21. Duration	Mean: 49 minutes 38 seconds (range: 23m14s - 78m23s)
22. Data saturation	Data-driven analysis was conducted concurrently with data collection and informed the point at which data were deemed sufficient. Sample size was therefore not determined prior to data collection but was dependent upon the 'richness' of the data acquired from interviews. Recruitment was stopped when data sufficiency (rather than saturation) was achieved.
23. Transcripts returned	Transcripts not returned to participants to protect anonymity within couples, in accordance with ethical review advice

Domain 3: Analysis and findings

Data analysis

24. Number of data coders	2/10 interviews were coded by a second analyst (EN) and discussed with first author (NW)
25. Description of the coding tree	See Appendix 5a; further information available on request from first author
26. Derivation of themes	Themes derived from the data, guided by developing framework which identified specific priorities for analysis in advance
27. Software	Text Analysis Markup System (TAMS) Analyzer, version 4.45b2ah
28. Participant checking	Participants were invited to provide feedback on a written summary of findings

Reporting

29. Quotations presented	Participant quotations presented to illustrate the findings and identified by participant pseudonym
30. Data and findings consistent	Consultation with second analyst and consultation group to help ensure consistency between the data presented and the findings
31. Clarity of major themes	Major themes presented under three main headings
32. Clarity of minor themes	Description of diverse cases and discussion of minor themes provided

Appendix 4. Semi-structured interview schedule

Overview of key topics with examples of questions; further prompts given in interviews as appropriate. Closed brackets indicate amendments for interviews with partners.

Overall Experience

- Can you start by telling me a bit about your experience of [// your partner] having had cancer?

Completing Treatment

- Before finally completing treatment, were you given any advice or support to help prepare for the end of treatment and the period afterwards?
- Can you tell me a bit about any ups and downs since finishing treatment?
- Have you had any contact with services since finishing treatment? (*If yes, What was that like?*)

Impact on Partner & Relationship

- Overall, have your experiences had any impact on your relationship as a couple?
- For some couples, the partner will attend one or more appointments. Other couples prefer that the partner is not present. Since the diagnosis, has your partner come with you [// have you gone] to any appointments or spoken with any staff? (*If yes, What was that like?*)
- Was there any support offered to your partner [// to you, as a partner]?
- Was your partner [// Were you] involved in your [// your partner's] care in any way?
- Do you think that the way your partner responded to situations made a difference to you? (*If yes, In what way?*)

General Opinion on Service Provision

- Thinking about your experiences of healthcare services, was there anything you found helpful or positive?
- And from your experiences of services, was there anything unhelpful or not positive?
- Thinking generally, is there anything [else] you think services could do to help couples or families adjust after treatment?

Additional Points

- Are there other things we have not yet spoken about which you would like to share?
-

Appendix 5a. Framework analysis stage 2: Developing framework

Theme or Code	Definition
1.1 The extent of the impact of cancer	
Physical Impact	Text relating to the physical impact or changes as a result of cancer or treatment
- Or None	
- Side-effects	Text relating to physical side-effects of treatment.
- Fatigue	Text relating to tiredness, exhaustion, the need for more sleep, or for more frequent or prolonged time in bed
- Complications	Text relating to any medical complication(s) or unexpected physical difficulties arising which disrupted treatment and recovery
- Straight-forward	Text relating to a perceived 'straight-forward' journey through treatment, without medical complications
Emotional Impact	Text relating to the emotional impact of their experiences with cancer (whether negative, positive, neutral or mixed).
- or None, by contrast	
- Shock	Text relating to an explicit or implicit reference to shock or surprise, difficulty believing reality of diagnosis
- or Not, by contrast.	
- Worry	Text relating to worry, anxiety, apprehension, fear, concern
- Low mood	Text relating to being down, depressed, low, unhappy
- Or Not, by contrast	
- Helplessness	Text relating to helplessness, that nothing can be done, no direct help can be given or received.
- Irritability	Text relating to Patient becoming short-tempered, moody, grumpy, impatient
- or Not, by contrast	
- Relief	Text relating to a feeling of relief, gladness an experience is over, happy to be finished
- or Not, by contrast	
Life Impact	Text relating to the impact of cancer on life more generally, including: work, finances, hobbies & interests, travel, holidays, social life, daily routine.
- or None.	
- Life Context	Text referring to participants' broader life context including other life events and adversity, current or historical.
Recovery	Text relating to recovery, adjustment, return to normal or near normal
1.2 Responses and coping styles	
Stoicism	Text relating to a stoical response including: <ul style="list-style-type: none"> - minimising or down-playing of difficulties (for instance, saying describing something objectively difficult as 'not a problem', 'no big deal', etc) - emphasis is given to being strong, determined, tough - responding to adversity by 'just getting on with it, carrying on', etc
Compare With Others	Text in which the participant draws a comparison between their own and others' experiences
Lucky	Text relating to being lucky, fortunate, grateful
- or Not, by contrast (unlucky, unfortunate)	
Humour	Either text in which the participant is describing humour as a response or

	in which the participant is being humorous or light-hearted within the interview itself
Distraction	Text relating to the use of some form of distraction or attempt to 'take their mind off it' as a way of coping.
Hope	Text relating to hope, optimism, focusing on the future, looking ahead, making positive future plans

1.3 Types of Social Support

Support>General	Text relating to general support, not specified whether emotional, informational or practical.
Support>Emotional	Text relating to Emotional support (= offering of empathy, concern, affection, love, trust, acceptance, intimacy, encouragement, caring, warmth, nurturance, valuing) and Companionship (= being with)
Support>Information	Text relating to Informational support (= provision of advice, guidance, suggestions, or useful information to someone)
Support>Practical	Text relating to Practical, Instrumental, Tangible support (= doing for: concrete, direct assistance, including medical/physical care such as symptom management, wound care, etc)

1.4 Sources of Social Support

Support>Patient	Text relating to support from the Patient (for the Partner)
Support>Partner	Text relating to support from the Partner (for the Patient)
Support> Healthcare System	Text relating to support provided by the Healthcare System including: Nurses (various types), Doctors (various types), Other Healthcare Professionals (various types)
Support> Wider Network	Text relating to support from the wider social network including: family, friends, neighbours, colleagues, other patients, other agencies or organisations
- Impact on Wider Network	Text relating to the impact on the wider network e.g. family members

2. Relationship: dynamics between the Patient and Partner

Overlap	An example of shared narrative, same or similar phrase used in connection with a situation, apparent concordance in comparison with data from the partner's interview
Contrast	A differing narrative, dissimilar account or opinion of a situation in comparison with data from the partner's interview
'We' experienced it together	Text in which the Participant describes a shared experience of the illness as something "we" went through or which affected "us."
Impact on Relationship	Text relating to changes described in the relationship between the Patient and their Partner related to the illness.
- Little or No Impact on Relationship	Text relating to little or no change in the relationship between the Patient and their Partner related to the illness.
- Positive impact on Relationship	Text relating to changes described in the relationship between the Patient and their Partner which are perceived as positive, such as feeling closer or no longer taking the other for granted.
- Challenges for Relationship	Text relating to changes described in the relationship between the Patient and their Partner which presented a challenge or strain.
- Unspoken	Text relating to things which were not said or openly discussed between Patient and Partner

- Needing Space	Text relating to the need for 'space' or independence, time away from each other, whether sought, given or not
Perception of Other	Text relating to the Participant's perception of their partner's thoughts, feelings or experiences (i.e. Patient re: Partner or Partner re: Patient)
- Worse for Other	Text in which the Participant indicates their belief it was worse or in some way more difficult for their partner.

3. Services: Experiences and Opinions of Health Care Services

Positive experiences of health care	Text relating to positive comments made about staff and the healthcare they provide
Negative experiences of health care	Text relating to any negative experience or opinion of staff or healthcare services
- Communication difficulties between Health Care Professional(s) and Patient or couple	Text relating to problems with communication between individual and healthcare professional(s) due to: participant not being given information; not being kept informed over time; difficulty understanding or retaining information; miscommunication between different Healthcare Professionals or between the patient and Healthcare Professional; participant's uncertainty over who to contact for information or support.
- Waiting	Text relating to waiting for cancer-related information of some kind (such as diagnosis, test or scan results, the 'all clear') or waiting for cancer treatment or for completion of treatment / discharge from hospital
- Left by Services	Text relating to feeling that he/she was 'left' by Healthcare Professionals/services (to get on with things themselves)
- Suggestions for service improvements	Text relating to a Participant's suggestion(s) for change(s) to healthcare services or of their personal preference(s) regarding healthcare provision
- Unmet needs	Text relating to any unmet need for additional support (medical, informational, practical, emotional, general) - or No unmet need, by contrast
Partner's encounters with health care team	Text relating to experience or opinion of the Partner's encounters with Healthcare Professionals
Treatment decision-making	Text relating to making decisions about treatment
Follow-up	Text relating to contact (follow-up care) with healthcare services after completion of treatment for colorectal cancer

Appendix 5b. Framework analysis stage 3: Indexing (Transcript sample)

Sample from transcript	Indexing
[I] And so, after she finished the chemotherapy and came home, what was that – or how has that time been? What's that been like?	
[D] Em, worrying for a start. Em, I mean, we both sort of try to keep calm and matter of fact, level-headed kind of thing. For [name of partner], obviously, it was a tense time, you know. 'Did it work? Did it not?' Em, for me, to a lesser extent, the same thing. You don't know how your future's going to be or what's going to happen. Obviously for [name of partner] it was a-, whether she'd go through another course of treatment or whether it was worse than that. Just, not knowing. Eh, takes- [coughs], sorry, takes a while from the last chemotherapy – or seems like a long time til you get your scan and then til you get your sort of results of the scan. And it must have been a fairly tense sort of thing for her, you know. For me, em, left wondering, obviously, you feel it as well but, em, bottom line it's not me that could be dying so, em, I suppose it affected me in a different way but, I mean, obviously being with somebody for a long time, eh, it's a partnership and you want the best for them, so, em. At least I was going to work and during the day, my mind was taking up with other things. Whereas she was mostly at home and I could tell it was having an effect on her, you know. Just, with any decision, you're waiting a few weeks to find out, 'Is it good or bad?' If it could affect the rest of your life, you want to know as quickly as possible. So, em-	Worry Stoicism Worse for other Waiting Worse for other Distraction
[I] In what way did you see it affecting her?	
[D] Just wanting to know the results and, you know, em, she'd be saying, 'Oh, I wish I could get the results, I wish this week would pass, I wish-' Three weeks went past and there's nothing you can do about it. Eh, what do you say to that, ken? You know, try to be positive, look for the best outlook. 'You're treatment's gone well, naebodys sort of given you a setback through your treatment hopefully,' etcetera, etcetera. Just trying to keep positive. But it was certainly a tense time for her.	Waiting (Overlap with patient) Helpless Hope Partner's support: emotional Worry
[I] Have there been any changes to your kind of lifestyle or day to day routine?	
[D] Em, not that much. Eh, [name of partner] retired couple of years ago and obviously I've kept working so we're not that long into that routine, you know, sort of. Em, but no, because she was at home, em, I don't know what I want to say. Eh, I suppose, it's a routine that she'd not long gone into. I don't know how it affected her during the day when I wasn't there. Evenings and nights we'll-, we don't go out much anyway so not much of it changed there. Obviously, em, questions she'd asked, or, you know, statements, 'I wonder how this is going to end up or what the outcome will be or sort of what the future holds,' that kind of thing but [coughs] day to day life kind of went on as normal. During the day, my time was taken up with other things. I sort of think, em, you know, what if things don't turn out well. You know, you think, what is the future going to be like. But it's not something we discussed. First you wait and see what it is. Then you deal with it. That's the sort of way we go. So, em, not a lot of changes to our lifestyle. But it was just a case of going through the treatment, hoping for a good result and waiting til we got the result before you start-, well, I say 'before you start worrying' – you start worrying the first treatment, but, em, before we sort of, we didn't, or I didn't plan for bad news. Wait and til it comes before, you know,	Context Unspoken Distraction Worry Unspoken (Overlap with Patient) Little or no impact 'We' Hope

there's a plan. We kind of went through it and hoped it would be positive.

[I] So, what contact has there been, since she finished chemotherapy, with services?

[D] Em, well, after the-, she got the results [coughs], for me no contact. For [name of partner], em, I don't-, well, she's up to her GP. Gave her GP sort of information that the hospital had given her, that type of thing. But other than that, nothing that I can think of.

Follow-up
Partner contact: none
Information

[I] Okay so there's just that one appointment, getting the results of the scan?

[D] Yeah, well, at the end of the chemo, they scan and then there's clinic, get the results. No I can't think of anything else. [coughing] Sorry

[I] No, don't worry – would you like a glass of water?

No I should be okay.

[I] So when you went in for that appointment to get the results, what was that like?

[D] Eh, it was okay. Em, obviously you go there not knowing the answer. Em, we weren't kept waiting too long but, you know, you're both sitting there saying relatively little to each other, thinking, 'Come on, come on – let me know.' And, but, as I said, we weren't waiting too long. Em, I can't remember the doctor's name she had but it wasn't him that took us. It was, em, I'm assuming an assistant. Thought then, 'Okay, if it's not him, maybe this is good news.' And so it turned out it was. But, well, it wasn't too bad. As I say, waiting for the result was a tense time, just sitting there. Em, luckily the TV was on – something to kind of distract you but, eh, okay apart from that.

Waiting
(Contrast with Patient)

Worry
Distraction

[I] Okay. So, since finishing, have there been any things that you hadn't expected or weren't prepared for?

[D] Mm, no, I wouldn't say so. Obviously getting our house ripped apart! [laughs] Aye, well the flat, should I say. But, eh, we didn't get time to sort of, em, take in the results, as I say. It was straight into that, there was work to do. Now we're sort of redecorating the place so it's going to be my evenings taken up by, you know, that sort of thing - sanding, painting, that sort of thing, so, em, no it's been busy. Strange, strange way to go but no we haven't fully spoken about anything.

Context

Unspoken

[I] Okay so overall, what's your opinion of the follow-up care.

[D] Eh, haven't thought about it. The result itself was good so great – hopefully we're finished with that. And, em, life can sort of- well, maybe never get back to normal as such. Once you've gone through that, it's got to leave an impression. Not so much for me but more for [name of partner]. But it was-, it was more, 'Good, that's out of the road, let's try and get on with things.' So, em, didn't even think about follow-up or anything like that.

Recovery
Relief
Life impact
Worse for Other
(Overlap with Patient)
Follow-up

[I]: Interviewer (NW); [D]: Participant ('David')

Appendix 5c. Framework analysis stage 4: Charting of key themes for dyadic analysis across dataset

	Arthur	Agnes	Beth	Bruce	Colin	Claire	Dawn	David	Evan	Emma
Recovery: factors facilitating or disrupting recovery from cancer										
Complications	0	0	3	0	3	0	5	1	0	0
(or straight-forward)	1	3	0	0	0	0	0	0	1	1
Patient low in mood	0	0	3	0	0	2	0	2	0	1
Patient showed increased irritability	0	0	5	5	2	2	0	0	3	1
(or Patient not irritable)	1	1	0	0	0	0	0	0	0	0
Life Context	0	0	1	1	3	2	3	5	7	0
Recovery	9	3	10	12	16	7	3	1	1	2
Stoicism	11	10	20	3	13	16	14	16	6	17
Hope	3	1	3	5	1	1	0	7	3	0
Support from Healthcare System	1	0	2	2	19	11	0	0	2	4
Support from Wider Network	1	1	11	13	0	5	2	0	3	4
Relationship: dynamics between the Patient and Partner										
Overlapping comment	2	2	6	6	5	5	3	3	5	5
Contrasting comment	0	0	3	3	2	2	1	1	4	4
‘We’ experienced it together	5	2	7	2	7	11	1	11	1	4
Little or No Impact on relationship	2	0	2	2	1	0	1	1	0	0
Positive impact on relationship	0	0	0	0	1	1	0	0	1	2
Challenges for Relationship	0	0	6	4	3	4	1	2	2	1
Unspoken	0	0	1	2	0	1	1	10	1	2
Needing Space	0	1	0	1	2	2	2	0	0	0
Worse for Other	0	0	0	1	1	0	1	4	0	1
Services: Experiences and Opinions of Health Care Services										
Positive experiences of health care	3	2	12	8	14	11	2	4	0	2
Negative experiences of health care	0	0	9	4	7	3	10	3	4	5
Communication difficulties with Healthcare team	2	1	4	1	6	1	8	10	4	3
Waiting	4	3	2	4	6	3	0	7	1	3
Left by Services	0	0	6	0	3	0	1	3	0	0

Numbers denote total instances of theme

Appendix 5d. Framework analysis stage 5: Diagram of conceptual links

Developing the framework and analysis included diagrammatic representation of emerging themes and conceptual links, as illustrated below (Figure 2, based on Fletcher *et al.*'s 2012 model).

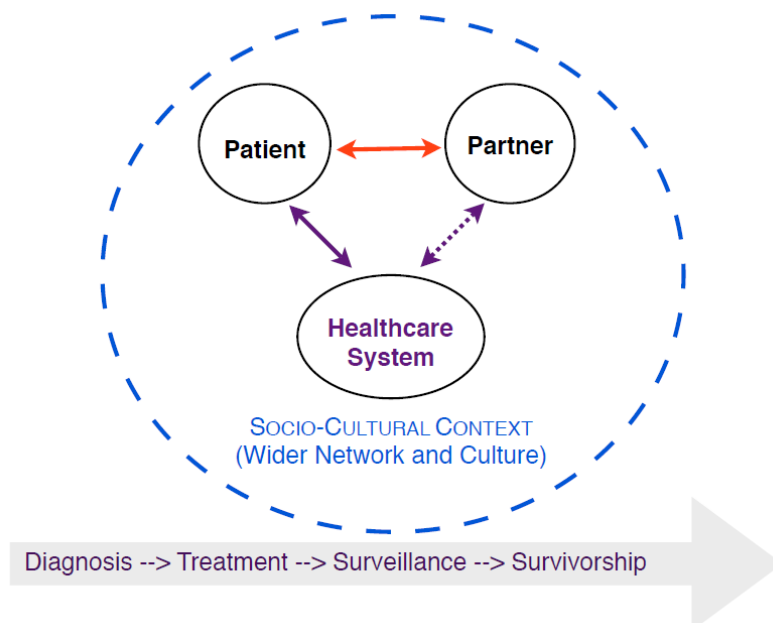


Figure 2. Diagrammatic representation of analytic framework

The patient-partner relationship dynamics are set in context alongside the interaction with the healthcare system. The dashed line denotes that, in some cases, the healthcare system may have limited or no direct contact with the partner. Even in situations where the healthcare staff and partner do not meet, the impact of both on the patient indirectly affects the other. These dynamics occur within a wider cultural context which influences the expectations, availability and allocation of resources and which affects the nature of relationships between the people involved. The arrow represents the recovery process across the trajectory for cancer survivors and their partners.

Appendix 6. Service user and carer consultation group recruitment flyer



Couples Facing Cancer

Help to plan a research project

To help **plan** a research project on couples' experiences of cancer care services, we are looking for people who have experience of services themselves.

It would include giving **feedback** on different parts of the project. For example, you may be asked for your opinion on:

- the Information Sheets given to people who are invited to participate
- the interview questions which participants are asked
- ways to make best use of the research findings.

It may involve meeting as a **small group** to **discuss** the project along with others who have been affected by cancer.

We are not yet looking for research participants. We are looking for **volunteers** to help **develop the research project** itself.

If you think you might be interested, please **contact us** to get more information.

You can then decide whether you would like to get involved on a one-off or ongoing basis, or not at all.



For more information, please contact:

Naomi White, Trainee Clinical Psychologist

Telephone: 01224 551 740 Email: naomi.white@nhs.net



Appendix 7. Service user and carer consultation group information sheet



RESEARCH PROJECT ON COUPLES' EXPERIENCES OF CANCER CARE SERVICES



What you should know before you agree to volunteer
as a consultant on the project:

- If you agree to volunteer, you may be asked to give feedback on one or more parts of the project, for example on Participant Information Sheets or possible interview questions.
- You do not have to give any feedback on the project. You are free to withdraw from involvement in the project at any time without needing to give a reason.
- We value all feedback and will carefully consider each person's comments.
- Some aspects of the project are not open to change due to constraints on the study. These include limited time and resources, as well as specific academic requirements for submitting the thesis. It may not be possible for all the ideas suggested by consultants to be put into action on this project. However, all feedback will be noted and may help to direct future research.
- There may be differences of opinion between people who are consulted. All volunteers are asked to respect others' opinions. The final decisions for this project will be made by the researcher.
- Any travel expenses will be reimbursed. Unfortunately, it will not be possible to provide reimbursement for volunteers' time.
- The project raises sensitive topics which some individuals may find upsetting. To speak to someone not involved in the project and seek further support, there are organisations you can contact, including:
Macmillan Cancer Support: 0808 808 00 00
CLAN Cancer Support: 01224 647000
- While we would value your feedback, your wellbeing is of paramount importance. If you think you are likely to find issues raised by the project to be upsetting, we would advise that you do not volunteer for this project at this time.

If you have any questions, please contact the researcher, Naomi White.
E-mail: naomi.white@nhs.net Tel: 01224 551 740

Appendix 8. Confirmation of ethical review and approval

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsqac.org.uk

Miss Naomi White
Roxburghe House
Ashgrove Road
Aberdeen
AB25 3BX

Date 29th November 2012
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss White

Study title: A multi-perspective study on couples' experiences of cancer care services
REC reference: 12/WS/0298

Thank you for your email of 29th November 2012. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 14 November 2012

Documents received

The documents received were as follows:

Document	Version	Date
Other: Lone Working Policy	August 2008	
Participant Consent Form	2	29 November 2012
Participant Information Sheet	2	29 November 2012
Protocol	2	29 November 2012

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Interview Schedules/Topic Guides	1	01 November 2012
Investigator CV		
Other: CV Supervisor - Dr Emily Newman		28 August 2012
Other: Lone Working Policy	August 2008	
Participant Consent Form	2	29 November 2012
Participant Information Sheet	2	29 November 2012
Protocol	2	29 November 2012
REC application		07 November 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

12/WS/0298	Please quote this number on all correspondence
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Yours sincerely

Mrs Liz Jamieson
Committee Co-ordinator

Copy to: Marianne Laird, Queen's Medical Research Institute
Dr Gail Holland, Research Governance Manager University of Aberdeen & NHS Grampian

West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhs.gov.uk

Miss Naomi White
Trainee Clinical Psychologist
NHS Grampian/University of Edinburgh
Roxburghe House
Ashgrove Road
Aberdeen
AB25 3BX

Date 14th November 2012
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss White

Study title: A multi-perspective study on couples' experiences of cancer care services
REC reference: 12/WS/0298
IRAS Project reference: 97349

The Proportionate Review Sub-committee of the West of Scotland REC 3 reviewed the above application on 13 November 2012.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated

Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Additional Conditions specified by the REC

The Sub Committee commented as follows

- 1) The title of the research did not reflect the study, i.e. Bowel Cancer. The Sub Committee requested that the Study Title be changed to 'A multi-perspective study on couples' experiences of Colorectal Cancer Care Services'. With the exception of the Application Form on IRAS which cannot be changed, the study documentation should be revised to reflect the new title.
- 2) The content of the Participant Information Sheet should be revised as follows:
 - To reflect the fact that the study is about 'bowel cancer' and not cancer care in general.
 - The name of the Ethics Committee should be changed to 'West of Scotland Research Ethics Committee 3'.
- 3) The Committee noted that interviews may be held outwith a clinical setting. In this regard a Lone Working Policy must be in operation. Please provide details of what will be in place in such situations.
- 4) The Consent Form should be revised to include consent to use anonymised quotations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview Schedules/Topic Guides	1	01 November 2012
Investigator CV		
Other: CV Supervisor - Dr Emily Newman		28 August 2012
Participant Consent Form	1	01 November 2012
Participant Information Sheet	1	26 October 2012
Protocol	1	25 October 2012
REC application		07 November 2012

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/WS/0298	Please quote this number on all correspondence
------------	--

With the Committee's best wishes for the success of this project

Yours sincerely



Liz Jamieson
Committee Co-ordinator
On behalf of Eoin MacGillivray, Vice Chair

Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers"

Copy to: Marianne Laird
Dr Gail Holland, Research Governance Manager University of Aberdeen &
NHS Grampian

Appendix 9. Participant Information Sheet



RESEARCH PROJECT ON COUPLES' EXPERIENCES OF COLORECTAL CANCER CARE



Information about the research for people who may take part

We would like to invite you and your partner to take part in a study on couples' experiences of colorectal cancer care services.

Before you decide if you would like to take part, please take your time to read and think about the following information.

What is the purpose of this study?

The aim of the study is to learn more about experiences of colorectal (bowel) cancer care services from the perspectives of people who have had bowel cancer and their partners. The focus will be on experiences as a couple and particularly what it was like after completing treatment. As the main researcher, I am carrying out this study as part of my Doctorate in Clinical Psychology.

Why have I been invited to take part?

The Cancer Nurse Specialist has identified that you and your partner may be suitable to take part in the study due to your past experience with bowel cancer.

Do I have to take part?

No, you do not have to take part in the study.

Both you and your partner are also free to withdraw from the study at any time, without having to give a reason. Your decision will have no effect on the standard of care you or your partner receives.

You will be given time (at least a day) to read and consider this information sheet before you are asked if you consent to participate.

What will it involve if we decide to take part?

If you would like to take part in the study, I will ask you to sign a consent form to show that you have read and understood this information and agree to participate.

If you and your partner both agree to take part and are suitable for the study, I will arrange to meet you and interview you separately. You would each be asked about your experiences of cancer care services and of completing treatment.

Each interview should last around 60-90 minutes. We can meet at a time and place that is convenient for you.

What will I have to do?

After consenting to participate, you will meet with me in person for a one-to-one interview. You will be asked to answer a number of questions about your experiences. You do *not* have to answer every question or speak about anything you would prefer to keep private. You can finish the interview at any time. If you would like to receive a copy of a summary of the study findings, this should be sent out some months after the interview. At that time, you will be invited to give any further comments if you would like.

Will my taking part in the study be kept confidential?

I will not tell anyone else about your decision to take part or not. If you are interviewed, I will not tell anyone else what you say in the interview unless you share information that makes me concerned about the safety of you, your partner or someone else. I would discuss this with you and may need to share this with my supervisor and seek further advice.

What will happen to the information I share?

The interview will be audio recorded. Afterwards, I will type up the interview. Names and other information which could identify people will be removed or altered to keep them anonymous. The audio recordings will then be deleted.

Anonymous quotes from the interviews will be included in the write-up of the study. Participants' quotes may be compared alongside quotes from their partner. It will be submitted as part of a doctorate in clinical psychology, sent to relevant scientific journals and shared with other health care professionals and researchers.

If I give consent to take part, will I definitely be interviewed?

No, unfortunately for a number of reasons I may not be able to interview everyone who wants to take part.

What if one of us wants to take part but the other does not?

It is expected that some people will want to take part and others will not. You are free to choose not to participate, even if your partner wants to. Your decision will not be shared with anyone else, including your partner. Only when both partners consent will interviews be arranged. Not every couple will go on to be interviewed.

What are the advantages and disadvantages of taking part?

If you decide to take part, I cannot promise that this study will have any direct benefit for you or your partner. However, some people find that talking to someone about their experiences can be helpful or interesting. Any information that you share helps us to learn more about the experiences of couples facing cancer and can help improve services for others in a similar situation.

Taking part involves giving up your own time. Sharing some experiences may be difficult. However, you choose what to say and can stop at any time. After the interview, there will be the opportunity for you to raise any questions or concerns. If there are concerns about your wellbeing, I can refer you to a relevant health care professional, with your permission. They would be able to offer further support or advice as necessary.

The study has been reviewed and approved by the West of Scotland Research Ethics Committee 3.

CONTACT DETAILS

If you would like to contact a member of the research team about the study, please contact:

Naomi White, Researcher Tel: 01224 557 078 naomi.white@nhs.net	Karen Gow, Colorectal Cancer Nurse Specialist Tel: 01224 554 111 karen.gow@nhs.net	Dr Margaret McLean, Research Supervisor Tel: 01224 557 081 margaret.mclean@nhs.net
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If you would like to seek independent advice about taking part in this study, you can contact:

Dr Angus Lorimer, Clinical Psychologist
Telephone: 01224 557 497

If you wish to make a complaint about the study, please contact:

NHS Grampian Feedback Service
St Martin's House, 181 Union Street, Aberdeen AB11 6BB
Telephone: 0845 337 6338
E-mail: nhsgrampian.feedback@nhs.net

Thank you for taking the time to read this information sheet. Do let me know if you have any questions.

Naomi White, Trainee Clinical Psychologist and researcher

Appendix 10. Consent form



RESEARCH PROJECT ON COUPLES' EXPERIENCES OF COLORECTAL CANCER CARE



Consent form

TITLE: Couples' Experiences Of Colorectal Cancer Care Services

NAME OF RESEARCHER: Naomi White

By initialling each box, you are agreeing to the following statements:

Please initial box

1. I have read and understood the information sheet about this study (version 2, dated 29.11.12). I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.	<input type="checkbox"/>
2. I understand that taking part in the study is voluntary and that I am free to withdraw from the study at any time, without my health care or legal rights being affected in any way.	<input type="checkbox"/>
3. I give permission for the interview to be audio-recorded.	<input type="checkbox"/>
4. I understand that, if the results of this study are presented or published, names and other identifying information will be made anonymous.	<input type="checkbox"/>
5. I give permission for anonymised quotes from the interview to be included in presented or published results of the study.	<input type="checkbox"/>
6. I understand that relevant sections of data collected during the study may be looked at by the researchers and individuals from the Sponsors (University of Edinburgh) where it is relevant to my taking part in this research.	<input type="checkbox"/>
7. I understand that the study is for the purpose of research and not for treatment.	<input type="checkbox"/>
8. I agree to participate in the study.	<input type="checkbox"/>
Participant name: _____	Name of person taking consent: _____
Signature: _____	Signature: _____
Date: _____	Date: _____

Thank you for your help

Appendix 11. Demographics form



RESEARCH PROJECT ON COUPLES' EXPERIENCES OF COLORECTAL CANCER CARE



PATIENT VERSION

PARTICIPANT CODE: _____

Please complete the following as best you can. Don't worry if you are unsure of exact dates.

1. Gender: ☐ Male ☐ Female
2. Age: _____ years
3. Ethnic origin:
☐ White ☐ Mixed / Multiple ethnic groups ☐ Asian
☐ Black ☐ Other ethnic group
4. Employment status:
☐ Employed ☐ Self-employed ☐ Unemployed ☐ Retired
5. Date of cancer diagnosis (*approximately*): _____
6. Treatment received:
☐ Surgery ☐ Radiotherapy ☐ Chemotherapy ☐ Hormone therapy
7. Date treatment completed (*approximately*): _____
8. Marital status: ☐ Married ☐ Cohabiting
9. Length of relationship with partner: _____ years

Thank you for your time

Page 1 of 1

Appendix 12. Participant debriefing and contact sheet



RESEARCH PROJECT ON COUPLES' EXPERIENCES OF COLORECTAL CANCER CARE



Thank you for taking part and sharing your experiences. We really value your time and contribution.

If you would like to contact a member of the research team about the study, please contact

Naomi White, Researcher Tel: 01224 557 078 naomi.white@nhs.net	Karen Gow, Colorectal Cancer Nurse Specialist Tel: 01224 554 111 karen.gow@nhs.net	Dr Margaret McLean, Research Supervisor Tel: 01224 557 081 margaret.mclean@nhs.net
---	---	---

If you would like advice or support, there are a number of different possible contacts, including:

Macmillan: 0808 808 00 00
<http://www.macmillan.org.uk/>

CLAN cancer support: 01224 647 000
<http://clanhouse.org/>

Bowel Cancer UK: 0800 8 40 35 40
<http://www.bowelcanceruk.org.uk/>

Beating Bowel Cancer helpline: 08450 719 301
<http://www.beatingbowelcancer.org/>

These are independent organisations with no connection to the research project.

An extended list of useful contacts can be found on the BBC website at:
http://www.bbc.co.uk/health/support/cancer_usefulcontacts_index.shtml

If you wish to make a complaint about the study, please contact:
NHS Grampian Feedback Service
St Martin's House, 181 Union Street, Aberdeen AB11 6BB
Telephone: 0845 337 6338
E-mail: nhsgrampian.feedback@nhs.net

Appendix 13. Author guidelines: Psycho-Oncology

Manuscript style. The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. It is not necessary to double-line space your manuscript. There should be a separate title page with full information and another page for an abstract, prior to the Introduction. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Figures should be uploaded as separate figure files.

- During the submission process you must enter the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs.
- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)**.
- Enter an **abstract** of up to 250 words for all articles. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work. Submit your abstract according to these headings: objective; methods; results; conclusions.
- Include up to six **keywords** which **must** contain the words cancer and oncology that describe your paper for indexing purposes.
- Research Articles should not exceed 4000 words (including no more than five figures and/or tables but excluding references). The limit for Brief Reports is 2000 words including no more than two tables or figures and no more than 20 references. Review papers of up to 6000 words will be considered - authors should contact the Editors for advice.
- Letters to the Editor should not exceed 400 words including a maximum of one reference. No figures or tables. Please note that if Letters to the Editor include a comment on a previously published paper the authors of said paper should be allowed 4 weeks in which to respond. If no response after 4 weeks the Letter will simply be accepted with an Editor's Footnote "The authors of [Title of Paper previously published] offered no comments".

All abbreviations except for SI symbols should be written in full the first time they appear. Generic or clinical names should be used for all compounds: materials and products should be identified. The species of any animals used should be stated precisely. Sources of unusual materials and chemicals, and the manufacturer and model of equipment should be indicated. materials and products should be identified in the text followed by the trade name in brackets.

Reference style. References should be cited in the text by number within square brackets and listed at the end of the paper in the order in which they appear in the text. All references must be complete and accurate. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. Where possible the [DOI](#) for the reference should be included at the end of the reference. Online citations should include date of access. References should be listed in the following style:

Decker, CL. Social support and adolescent cancer survivors: A review of the literature. *Psycho-Oncology* 2007; **16** : 1-11.

Peterson AC, Leffert N. What is special about adolescence? In *Psychosocial Disturbances in Young People: Challenges for Prevention*, Rutter M (ed.).Cambridge University Press: Cambridge, 1997;3-36.

Illustrations. Upload each figure as a separate file in either .tiff or .eps format, with the figure number and the top of the figure indicated. Compound figures e.g. 1a, b, c should be uploaded as one figure. Tints are not acceptable. Lettering must be of a reasonable size that

would still be clearly legible upon reduction, and consistent within each figure and set of figures. Where a key to symbols is required, please include this in the artwork itself, not in the figure legend. All illustrations must be supplied at the correct resolution:

Black and white and colour photos - 300 dpi

Graphs, drawings, etc - 800 dpi preferred; 600 dpi minimum

Combinations of photos and drawings (black and white and colour) - 500 dpi

Tables should be part of the main document and should be placed after the references. If the table is created in excel the file should be uploaded separately.

Colour Policy. Where colour is necessary to the understanding of the figures, colour illustrations will be reproduced in the journal without charge to the author, at the Editor's discretion.

Post Acceptance

Further Information. For accepted manuscripts the publisher will supply proofs to the submitting author prior to publication. This stage is to be used only to correct errors that may have been introduced during the production process. Prompt return of the corrected proofs, preferably within two days of receipt, will minimise the risk of the paper being held over to a later issue. Free access to the final PDF offprint of your article will be available via [Author Services](#) only. Please therefore sign up for Author Services if you would like to access your article PDF offprint and enjoy the many benefits the service offers.

Authors Resources: Manuscript now accepted for publication?

If so, check out our suite of tools and services for [authors](#) and sign up for:

Article Tracking

E-mail Publication Alerts

Personalization Tools

Cite EarlyView Articles

To link to an article from the author's homepage, take the DOI (digital object identifier) and append it to "http://dx.doi.org/" as per following example:

DOI 10.1002/hep.20941, becomes <http://dx.doi.org/10.1002/hep.20941>.

To include the DOI in a citation to an article, simply append it to the reference as in the following example:

Oestreicher, N., The cost of adjuvant chemotherapy in patients with early-stage breast carcinoma, *Cancer* **10(1)**, pp. 2054 - 2062, DOI: 10.1002/cncr.21464.

Online Open

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. For the full list of terms and conditions, see http://wileyonlinelibrary.com/onlineopen#OnlineOpen_Terms.

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form available from our website at:

https://authorservices.wiley.com/bauthor/onlineopen_order.asp

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

Appendix 14. Author guidelines: Journal of Cancer Survivorship

Title Page

The title page should include:

- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address, telephone and fax numbers of the corresponding author

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

- Purpose (stating the main purposes and research question)
- Methods
- Results
- Conclusions
- Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.
Implications for Cancer Survivors

Manuscripts are typically 15-20 double-spaced typed pages. Table and figures should be limited to 3-4 total. If you think your article will be significantly shorter or longer than that average, please include an explanation along with your submission.

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscripts with mathematical content can also be submitted in LaTeX.

LaTeX macro package (zip, 182 kB)

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section before the reference list. The names of funding organizations should be written in full.

Scientific style

Please always use internationally accepted signs and symbols for units (SI units).

Please use the standard mathematical notation for formulae, symbols etc.:

Italic for single letters that denote mathematical constants, variables, and unknown quantities
Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative)

Bold for vectors, tensors, and matrices.

Citation

Reference citations in the text should be identified by numbers in square brackets. Some examples:

Negotiation research spans many disciplines [3].

This result was later contradicted by Becker and Seligman [5].

This effect has been widely studied [1-3, 7].

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

The entries in the list should be numbered consecutively.

Journal article

Smith JJ. The world of science. *Am J Sci.* 1999;36:234–5.

Article by DOI

Slifka MK, Whitton JL. Clinical implications of dysregulated cytokine production. *J Mol Med.* 2000; doi:10.1007/s001090000086

Book

Blenkinsopp A, Paxton P. Symptoms in the pharmacy: a guide to the management of common illness. 3rd ed. Oxford: Blackwell Science; 1998.

Book chapter

Wyllie AH, Kerr JFR, Currie AR. Cell death: the significance of apoptosis. In: Bourne GH, Danielli JF, Jeon KW, editors. *International review of cytology*. London: Academic; 1980. pp. 251–306.

Online document

Doe J. Title of subordinate document. In: *The dictionary of substances and their effects*. Royal Society of Chemistry. 1999. <http://www.rsc.org/dose/title of subordinate document>. Accessed 15 Jan 1999.